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Risk and HIV-serodiscordant Couples in Porto Alegre, Brazil: "Normal" Life and the Semantic Quarantine

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Risk and HIV-serodiscordant Couples in Porto Alegre, Brazil:

"Normal" Life and the Semantic Quarantine

by

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A dissertation submitted in partial fulfillment
of the requirements for the degree of
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ABSTRACT

The objective of this research was to develop a holistic understanding of how risk, especially the risk of HIV transmission, is constructed and negotiated in the daily lives of a group of heterosexual, HIV-serodiscordant couples in Porto Alegre, Brazil. Couples serodiscordant for HIV are those in which one partner is infected and the other is not. Data were gathered through participant observation and semi-structured interviews with serodiscordant couples, as well as key informants in HIV/AIDS-related civil society, government, and biomedical practitioners in Porto Alegre. Interviews were recorded and transcribed and relevant study materials were coded and subjected to thematic and ethnographic discourse analysis. Many studies of HIV/AIDS assume that risk is a natural fact, objectively verifiable and meaningfully quantitative, but this dissertation problematized such constructions, seeing risk for HIV and the condition of serodiscordance as contingent and polysemic. This research also examined participating couples’ experiences with HIV for evidence of commodification or practices of biomedically-mediated citizenship.

The main finding of this study indicates that the sociocultural management of seropositivity is much more challenging than its relatively unproblematic biomedical management might lead one to expect, primarily due to the pervasiveness of AIDS-related stigma. Participating serodiscordant couples evidenced attempts to manage this stigma through recourse to a suite of linguistic strategies I call the “semantic quarantine,”
which discursively isolates the relationship and its constituent members from lexical elements associated with stigmatized identities. The ultimate goal of the quarantine is to create a reality where these couples’ intimate relationships are stripped of their threatening connotations, and constitute a “livable love.”
CHAPTER 1: INTRODUCTION
The Unmaking of Assumptions

“With the constant shooting that goes on around here, it’s easy to see AIDS as less threatening than dying of a gunshot wound,” said the particularly well-spoken Afro-Brazilian woman seated in front of me.1 Beside her, her female colleague nodded in rueful but complete agreement. The paradigm shift occurring in my brain was so profound I feared it would be audible.

AIDS, Acquired Immune Deficiency Syndrome, is the cause of millions of deaths worldwide, as well as a global “epidemic of signification” (Treichler 1987). For these two directors of a non-governmental organization (NGO) dedicated to the empowerment and assistance of minority women, however, the disease was epiphenomenal. Despite the location of their office in a neighborhood with one of the highest prevalence rates in Porto Alegre (Barcellos et al. 2006), they were telling me that, for the women they served, AIDS was not a pressing concern.

I thought back to an hour previously, when I had been lost in that very neighborhood, searching for the two-story house-cum-headquarters where we were talking now. On that winter mid-morning, there had not been many people outdoors, so the surroundings had my full attention. Negotiating the broken, often garbage-strewn sidewalk while giving wide berth to both stray dogs and the gaping gutters with their stagnant liquid (Greywater? Blackwater? I couldn’t tell), I intermittently scrutinized the residences I passed. Some were tiny and

---

1 Interview, 19 June 2007
ramshackle, with wooden or exposed brick walls, and corrugated aluminum roofs. Others were two-storied, with large windows and tiled roofs, potted plants blooming from upstairs verandas. The brick walls of these homes had been neatly plastered and painted cheery colors. Virtually all were hemmed in by a thicket of power lines, some from the electric company, some private, pirating from neighbors. Most of the doors and windows were covered by metal bars meant to block access by intruders.

The people I had seen appeared to be largely in transit to or from bus stops or the large, municipal health center, which was located not far from the NGO. The imposing building had few windows, and rust streaked down from many of the few it did have. Exposed walls everywhere were covered with graffiti. There was an unmistakable air of disrepair, if not disregard. Interestingly, right here, in the middle of a neighborhood where AIDS had faded into the background of other worries and challenges, were Brazil’s first municipal HIV counseling and testing center, and Porto Alegre’s first (and for more than a decade, only) municipal “specialized clinic” for treating HIV/AIDS and STIs. I felt sure I had reached the heart of something important, although I wasn’t certain what that something was.

It was around this same time that I first visited the municipal AIDS clinic, as well as the city health department’s epidemiological surveillance office. The NGO director’s comment stayed with me, though, coloring and complicating my interpretation of what I subsequently saw and heard. The clinic staff, many of them obviously dedicated to their work, related their impression of the changing demographics of the patient population, which I later found reflected larger trends in epidemiological data on AIDS in the city and nationally. Patients survived longer, but were poorer and had fewer years of formal education than those of the past. The reaction to these changes, on the part of the professionals who were confronted with them in
their daily work, ranged from partial recognitions of the structural challenges such populations face, to implicitly condemnatory evaluations (offered as asides to me) of patient choices.

In response to questions about access to the public health system, for example, one public health professional acknowledged challenges: “The most disadvantaged AIDS patients—they have access, they do. But they find themselves in such difficult conditions, so many social problems…” (interview, 20 June 2007). On the other hand, at the clinic, I heard healthcare workers complain several times that patients contracted HIV purposely, in order to obtain welfare assistance, though no individual was ever identified as an example. One biomedical practitioner I spoke to specifically lamented the tendency of HIV-positive women to keep “popping out” babies (this is a paraphrase, but one I stand behind), saying that “Every year they’re back with another one” (interview, 20 June 2007). Full of compassion for the children she treated, this health professional was perhaps not as understanding of their mothers.

All of this ambivalence was not limited to those whose connection to AIDS was purely professional. When I asked clinic patients about Brazil’s famous National AIDS Program, a frequent response was, “On paper, it’s a great system, but in practice…” (e.g., interview, 20 June 2007). I realized, upon my return from that first trip to Porto Alegre, that the all-important “rest of the story” might need to be excavated from such “trailings-off.” There was meaning in absence, in the silences of these narratives.

Whether tinged with moral disdain, or discouragement rooted in practical considerations, the perspectives of all the biomedical and public health professionals I talked to during 2007 had something very basic in common. They viewed AIDS as a terrible affliction, to be avoided at all costs. In addition, they deprecated inability or unwillingness on the part of HIV-positive patients to adopt biomedical interpretations of AIDS and attendant behavioral prescriptions, seeing this as
a sort of “failing.” Such attitudes immediately called to mind the distinction between “sanitary citizens” and “unsanitary subjects” that figured in Briggs and Mantini-Briggs’s (2003) work on the cholera epidemic of 1992-1993 in Venezuela. But unlike the Warao, some of the populations affected by HIV/AIDS in Porto Alegre didn’t merely dissent from official views on the causation of the epidemic; they disagreed, fundamentally, with assessments of its importance.

This seemed to be more than a health-related manifestation of different social positions, or access to resources and decision-making power; it seemed like a head-on collision of different realities. I wondered what implications this variation in meaning across sectors of society might have. I also questioned previously taken-for-granted assumptions about risk and disease, and about what makes human life meaningful.

In light of this, being open to alternative interpretations of risk for HIV was clearly necessary. Turning to the academic literature, I discovered a handful of pieces that presented just such perspectives. In particular, Abadía-Barrero’s (2002) work with marginalized children in Brazil (both HIV-positive and not) and Crane et al. (2002), reporting on HIV-serodiscordant heterosexual couples in California, provided support for the idea that under certain conditions an AIDS diagnosis could be beneficial. In a different context, Zaloom (2004:365) insightfully explored the “active, voluntary engagement with risk.” These authors collectively suggested new lenses through which to analyze the situation in Porto Alegre. By far the most influential, however, was João Biehl’s (2007) Will to Live: AIDS Therapies and the Politics of Survival. Engaging the topic of AIDS treatment in Brazil at multiple scales (international, national, local), yet remaining connected to the lived experience of socially marginalized HIV-positive people, it had a profound impact on the questions guiding this research. I felt I recognized many of the dynamics Biehl discussed; I wondered if his analysis explained what the patients sitting next to
me in the clinic waiting room meant when they failed to finish their sentences. All of this work has in common a political economic approach, which highlights stratified access to power and resources as a motivation for, and explanation of human behavior. Although I eventually took insights from all of these scholars in different directions, notions of unsanitary subjects, the commodification of risk, and the practice of patient citizenship were fundamental to the conception of the research reported here.

A final note on the evolution of this project is warranted. After identifying heterosexual HIV-serodiscordant couples as the population targeted by this research on risk, I anticipated that political economy would provide the theoretical framework for analysis, being supplemented by attention to discourse. Indeed, the original conception of this study was to situate couples’ practices and perspectives in political economic and historical context, including attention to current AIDS-related activism and experiences with treatment. However, as data collection and analysis progressed, it became evident that such an approach would not adequately explain the variation in the sample. In addition, several notable features of discourse manifested across participating couples, suggesting an alternative paradigm might generate deeper insight. While both political economy and discourse were both envisioned as conceptual tools for this project at the outset, the research findings led to an inversion of the priority accorded to each. Hence, in this dissertation, though considerations of access to resources and power undergird my ideas about what kinds of discursive performances are available to particular kinds of people, the focus is on the way couples both understand and enact their everyday reality through discourse.

**Overview of the Dissertation**

The foregoing section presented what I think of as the “genealogy” of this research. Rather than being an exercise in self-involvement, I believe this attempt to explain the
experiential and theoretical antecedents to which my scholarly work responds is necessary. Such formative influences deserve explicit recognition, both as a matter of intellectual debt, and as a guide for readers. In addition, the exposition serves the purpose of recognizing my acceptance of subjective experience as a “scientific position of speech…spoken from a moving position already within and down in the middle of things, looking and being looked at, talking and being talked at” (Pratt 1986:32). This conception is fundamental to the dissertation; therefore it is purposefully that I begin with such an account. In the rest of this section, I provide a brief overview of the chapters to come, signaling the intent or most important contents of each one. Subsequently, I list the research questions that orient this project and summarize the major findings.

Chapter 2 acquaints the reader with the socio-cultural, epidemiological, and political-economic context of the research site. This discussion touches on multiple scales, ranging from the international to a particular clinic in Porto Alegre, Brazil. The logistics, effectiveness, and routinization of the biomedical management of AIDS is an important topic, as is the persistence of AIDS-related stigma in this setting. The details included in the chapter constitute the justification for the project, as well as providing the background necessary for making sense of the findings.

Chapter 3 provides a selective overview of scholarly perspectives on sex-related risk for HIV, primarily from the fields of Anthropology and Public Health. The review yields important insights regarding the way approaches to risk have evolved, as well as bringing to light factors that can be expected to play important roles in the production of HIV risk in Porto Alegre. These include context-specific notions of gender, sexuality, and reproduction; political economy; and the nature of “serodiscordance.” Overall, the chapter argues for the importance of critical,
holistic considerations that understand risk for HIV, and the virus itself, as contingent and polysemic.

Chapter 4 details the design of this research, as well as the methods used in data collection, and the steps taken in analysis. Anthropological methods of participant-observation and interviewing were conducted with various stakeholders in the “world of AIDS” in Porto Alegre, during three field visits, over seventeen months. Government officials, biomedical and public health professionals, representatives from civil society, seropositive patients, and members of HIV-serodiscordant couples all participated, although the focus in this dissertation is on the data collected from six, heterosexual serodiscordant couples. These data were subjected to thematic and ethnographic discourse analysis.

Chapters 5, 6, and 7 each present and analyze data; it is largely on the basis of the collective findings from these chapters that I answer the research questions that orient this study. Each chapter has its own modality of presentation and analysis. Chapter 5 begins with an explanation of my approach to discourse, and includes a short section highlighting important dynamics at play across couples: social class or current economic situation; gender, sexuality, and reproduction; serostatus; and stigma. The ground thus prepared, individual “sketches” of each participating couple are intended to convey the personalities, history, and texture of life that prevail within the dyads. The totality of the sketches attests to the contingency and multiplicity of “serodiscordance” as a lived phenomenon.

Chapter 6 executes a fine-grained analysis of particular aspects of discursive production across couples, with the object of elucidating the mechanics behind the construction and negotiation of risk. I first consider the content and meaning of what I call the “discourse of normality.” Speakers’ intentions to the contrary, this discourse reveals the persistence of HIV-
related stigma, and seronegativity as the unspoken norm by which the quality of one’s life is evaluated. After using a case study approach to illustrate subtle patterns in one participant’s discursive production with respect to HIV transmission, I then trace these same patterns throughout the talk produced by the whole sample, to demonstrate how constructions of risk manifest, and are created, through discourse.

Specifically, the three most common words for discussion of HIV transmission, contamin*, passar, and pegar, are analyzed; differences in usage based on the speaker’s relationship to the referent are clear. Overall, I interpret the special constraints that characterize talk about seroconversion within these couples as reflecting a collaborative resignification of serodiscordance and risk. This re-imagining is effected through a suite of linguistic strategies I call the “semantic quarantine,” that is, the discursive isolation of the relationship and its constituent members from lexical elements associated with stigmatized identities. The ultimate goal of the quarantine is to create a reality where these couples’ intimate relationships are stripped of their threatening connotations, and constitute a “livable love.”

Chapter 7 takes a different approach to the hunt for constructions of risk. It draws on the initial impetus for this research by asking whether actions taken (or not taken) by these HIV-serodiscordant couples can be seen as motivated by understandings of risk that deviate from hegemonic biomedical notions. In particular, I address constructions that posit risk for HIV, or the virus itself, as an opportunity; as a commodity; or as a basis for the exercise of citizenship. Anecdotal reports from the clinic notwithstanding, no evidence was found of opportunistic approaches to HIV risk among this sample. Few data support the common practice of patient citizenship (Biehl 2007), although some potential parameters structuring such expressions are discussed. Potentially more relevant was a specific variant of commodification, called clientship
by various scholars (e.g., Meinert et al. 2009; Richey 2012). Given Brazil’s history, this suggested the application of institutionalized strategies for dealing with social and material inequality to the therapeutic domain, rather than the development of new strategies for relating to the state. The implications of these findings in terms of doctor-patient relationships, as well as the emancipatory potential ascribed to patient-citizen identities are explored.

Finally, in Chapter 8, I provide a chapter by chapter review of the dissertation, and a streamlined discussion that, holding the main findings of this research finally in the same frame, answers the research questions animating this scholarly effort. I then offer recommendations based on this study, and the past and planned dissemination of findings, as well as an area for future research, are briefly noted. I conclude with a short reflection on AIDS-related stigma and the power of discourse to shape life in human collectivities.

**Research Questions and Major Findings**

The research questions that structure this dissertation are the following:

RQ1: What place does HIV occupy in the everyday lives of a sample of heterosexual, HIV-serodiscordant couples in Porto Alegre, Brazil?

RQ2: How is risk, specifically the risk of HIV transmission, constructed and negotiated by these couples?

RQ3: More specifically, do these couples conceive of risk for HIV or the virus itself as an opportunity (Zaloom 2004) or a commodity (Crane et al. 2002, Abadía-Barrero 2002,) that can be exchanged for goods, services, or social inclusion/status? To what extent do they engage in what has variously been called biological or patient-citizenship on the basis of HIV/AIDS (Petryna 2002, Biehl 2007)?

While the foregoing chapter overviews hint at more detailed answers to these questions, here I would like to offer the briefest possible summation, to prepare the reader for the much more comprehensive response given in the body of this dissertation. The heterosexual HIV-serodiscordant couples in this sample often seemed to consider the virus simultaneously not-at-
all important, and all-important. This apparent contradiction is produced by the confluence of several forces: scientific advancements in HIV treatment that render infection a “chronic”—which is to say, manageable—health condition; the ideological orientation, legal structure, and logistics of the public health system in Brazil that provides access to that effective treatment; and the hegemonic meanings associated with the virus that make sociocultural management of seropositivity much more challenging than its relatively unproblematic biomedical management might lead one to expect.

Much of the data and analysis reported here revolve around this last consideration, because concern over AIDS-related stigma arose spontaneously throughout my interactions with participating couples. Although they exhibited diverse ways of living “serodiscordance,” and varied responses to the possibility of HIV transmission, each of them had to confront not only the preconceito (stigma or prejudice) held by other people in their lives, but also, frequently, the stigma the members themselves had internalized. While the persistence of this challenge makes evident the constitutive role of culture in drafting collective expectations about what life can or should be like, the astounding power of human agency and ingenuity shines through in the couples’ ability to respond to that challenge.
CHAPTER 2: SETTING

Introduction

The present chapter provides the reader with an introduction to the context of the research presented in this dissertation. My goal is to communicate not only what I thought it important to know before I went to the field—that is, the cultural and epidemiological background that justifies the project—but also the knowledge I considered indispensable upon my return, without which the findings lose their anchor.

In the first section, I focus on the fieldsite for this research: Porto Alegre, the capital of Brazil’s southern-most state of Rio Grande do Sul. I provide a brief overview of sociodemographic indicators, as well as the fundamental notion of “difference” that characterizes the self-conception of the region’s inhabitants. Since the justification for this research derives in part from the specific contours of the epidemic in the Southern region, in the second section I survey the epidemiological context of Porto Alegre and briefly describe relevant policies enacted in response.

In the third section, I summarize the history and epidemiology of HIV/AIDS in Brazil, although the story is much more complicated than can be done justice to here. In the fourth section, I note how the basic structure of Brazil’s national health care system, specifically the move to municipalize the provision of all health care, has implications for the way seropositive individuals experience treatment for HIV.

In the fifth section I explore how one particular clinic has changed over the course of the epidemic, and how it typically functions today. Within the description of clinic flow, I offer
observations on the way biomedical practitioners disseminate information and attempt to compel particular behaviors from patients. Finally, I detail the rights and benefits available in this context to people living with AIDS. Woven throughout these last two sections is a discussion of patient perceptions and fears of HIV-related stigma, which may be contextually as important as AIDS incidence or public health infrastructure to gaining an understanding of the experience of seropositivity in Porto Alegre.

**The Fieldwork Context: Porto Alegre, Brazil**

**Selected Demographic and Socioeconomic Indicators**

Porto Alegre is the capital of Rio Grande do Sul (RS), Brazil’s southernmost state. The heart of a bustling urban center, in 2008 it boasted a 7th place ranking among Brazilian cities in terms of Gross Domestic Product (Soares 2010), and was the tenth most populous city in the country. According to the 2010 Demographic Census (IBGE 2010), the population of Porto Alegre proper was 1,409,351, while the “metropolitan region” was home to in excess of 4.5 million people. Of these, 48.2% was male; 51.8% female. The gender imbalance was more pronounced within city limits, with 53.6% of the population being female.² Another notable characteristic of the city’s population is its rising average age. Brazil in the 20th century underwent one of the fastest demographic transitions in the world (IBGE 2010:23); hence, the population is becoming older, on average. Porto Alegre’s population exemplifies this trend, albeit to a greater degree than is the case nationally. In 2010, for the first time, Brazilians 60 years of age and older constituted 10% of the country’s population; in Porto Alegre that year, the proportion was 15% (IBGE 2010).

² This relative dearth of men was common knowledge, and spontaneously offered by several female participants in this research as part of the explanation for the prevailing sexual double standard that constructed male infidelity as “inevitable.”
The city’s ethnic composition reflects the area’s history, including its initial settlement by groups from the Azores and waves of subsequent immigration to the state from Germany and Italy. In 2010, an overwhelming majority of residents (79.2%) declared itself *branco* (“White”). The next largest ethnic groups were *preto* (Black) and *pardo* (mixed), each claiming approximately ten percent of the population. East Asians and Indigenous groups together accounted for less than 0.5% of the city’s population. This breakdown differs dramatically from national statistics, in which Whites figure much less prominently (47.7%) and *pardos* are significantly better-represented (43%).

Given the over-representation of Afro-Brazilian populations among the poor in Brazil (Stepan 2007), it is not surprising that, in this predominantly-White city, mean income surpasses national averages. At the time of the 2010 Census, the minimum monthly salary for formal sector employment in Brazil was R$510 (roughly U.S. $300), and many statistics are reported in terms of the number of minimum monthly salaries a household or individual earns. In Porto Alegre, approximately 10% of the city’s 508,456 permanent private households earned either one minimum salary or less, or only received government benefits. On the other end of the spectrum, 7.4% of households earned the equivalent of more than 20 minimum salaries per month. In comparison, among urban populations nationally, 60.9% of households earned one minimum salary or less, or only received government benefits, while 0.5% fell into the highest-earning bracket of 20 minimum salaries or more. (IBGE 2010).

By other measures as well, conditions of life in Porto Alegre are better than average in Brazil. In the city proper, 93.9% of households enjoyed what the *Instituto Brasileiro de Geografia e Estatística* (Brazilian Institute of Geography and Statistics), or IBGE terms “adequate” sanitation, which indicates connection to a sewer system or septic tank, piped water,

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3 The approximate exchange rate for the Brazilian real during 2010 was 1.7:1 USD.
and garbage collection service (IBGE 2010, 2011).\textsuperscript{4} Nationally, only 61.8% of households fall into this category. Life expectancy at birth in the South, the larger region to which the state of Rio Grande do Sul belongs, is the highest in the country, surpassing the national average of 72.1 by more than two years (IBGE 2009:31).\textsuperscript{5} In terms of illiteracy, while 9.6% of those 15 and older nationally cannot read (IBGE 2010), in Rio Grande do Sul only 4.5% of the same age group is so-disadvantaged (IBGE 2010: *Tabelas* 4.23.1.2, 4.23.4.3). In Porto Alegre proper, illiteracy among those 10 and older is reported at 2.2% (IBGE 2010:*Tabela* 4.23.4.1).

These kinds of advantages have long accrued to city dwellers, and constitute one motor for the extensive urbanization that occurred in Brazil during the 20\textsuperscript{th} century. The most urbanized regions of the country, including the South, became more urban than rural over the decade of the 1960s, and by 1980 over 62% of the South’s population lived in cities (IBGE 2001:16, *Tabla* 6). As of the 2010 Census, 85% of the population of Rio Grande do Sul lived in urban areas (IBGE 2010:*Tabela* 4.23.1.1), mirroring the national statistic of 84.4% (Pinheiro 2011).

**Difference: Geographic, Cultural, Linguistic, and Historical Factors**

The snapshot offered by the above statistics reveals that the population of Porto Alegre is—in aggregate—whiter, wealthier, and advantaged in many ways when compared to Brazilians nationally. However, what the numbers do not capture is the pervasiveness and value accorded the notion of difference, and the degree to which it has been reified into a force that animates the identity of the Brazilian South (see map with color-coded regions in Appendix). Even in a nation famous for regionalism (Skidmore 1999), the residents of Rio Grande do Sul, called

\textsuperscript{4} Malathronas (2003:460) suggests that this may be partly attributable to the practice called Orçameto Participativo, or “Participatory Budgeting,” for which Porto Alegre is justifiably famous. He notes that in 1989, prior to OP, 49% of the population had “proper running water; in 1998, the proportion was over 98%.” OP appears briefly later in this chapter.

\textsuperscript{5} Municipal level data from the 2010 Census have not yet been published.
Gaúchos, “like to parade their…differentness from other Brazilians in their every step and gesture” (Malathronas 2003:440). Many factors contribute to this sense of difference, and while only some have consequences that directly impinge upon the realm of health, because it is an ever-present backdrop to life in Porto Alegre, it is important to at least sketch the general dynamics at play.

Geography is one factor that figures prominently in articulations of Rio Grande do Sul’s distinctiveness—from Gaúchos and other Brazilians alike. Its location (Porto Alegre lies at 30°00'S, 51°14'W) confers on the state a subtropical climate with four distinct seasons, in contrast to most of the rest of Brazil. Snow occasionally falls in the state’s mountainous interior, a draw for domestic tourists. The capital, at a lower elevation on the bank of the Guaíba River, does not see snow but can experience freezing temperatures in the winter months (June, July, and August). One health consequence of the climate is a predictable seasonal spike in respiratory infections, including the 2009 outbreak of H1N1 influenza. At 8.6/100,000, The South had the highest incidence rate of confirmed H1N1 cases of all regions of the country (Oliveira et al. 2009:4) and the mortality rate was nearly three times the national average (Yokota et al. 2011).

During a several-week period of the fieldwork for this research, it was common to see people wearing surgical masks in public. I was told this was not typical, but a response to the gravity of the perceived threat posed by H1N1.

Geography also impacts the city during the muggy summer months. Despite Rio Grande do Sul’s extensive coastline, Porto Alegrenses lament the lack of picturesque beaches, common in many of Brazil’s other states. Nonetheless, those with the means to do so typically escape to the beach for vacation and on weekends in January, February, and March. This may contribute to the fact that, in contrast to other Brazilian cities (notably Rio de Janeiro, São Paulo, and
Salvador), *Carnaval* does not figure in the city’s imagination as a time for samba and *fantasias* (the costumes dancers wear in parades). Instead, it is time to travel, preferably out of state.

Indeed, the Brazilian South, of which Rio Grande do Sul is the archetypal example, has its own cultural iconography, derived from ideas about rural lifeways (but see Oliven 1999, 2000 on the invention of this tradition). While Brazil is represented in the popular imagination by soccer and *Carnaval*, the South is symbolized by the independent, “hyper macho” (McCann 2012) *gaúcho*, or cowboy, on his horse. Southern Brazilians share this word with their Uruguayan and Argentinian neighbors (although pronounced slightly differently), but, as mentioned previously, it also has come to mean someone from the state of Rio Grande do Sul, despite the fact that it is principally at the borders that the *gaúcho* typified life in the state. As Malathronas (2003:440) notes, “It is as if the leading intellectuals of Rio Grande do Sul have picked the gaucho cowboy as an emblem and are constructing a kind of state nationalism….Such independence requires people who not only feel different, but have also been told again and again that they *should* feel different.”

These messages about difference are impossible to miss. If *samba* and *bossa nova* are the recognized rhythms of the Brazilian national soundtrack, the South sways to its own music, which frequently features the accordion, and characteristic rhythms and rhyme-schemes (McCann 2012). If the beverage that comes to mind in conjunction with Brazil is coffee or *caipirinha*, *Gaúchos* are ubiquitously pictured sipping *chimarrão* (a tea similar to its more famous Argentinian cousin, *mate*) out of a gourd with a silver straw. Finally, in contrast to

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6 Interestingly, this image of hyper-masculinity co-exists with pervasive beliefs about a high frequency of male same-sex sex. Many Brazilian friends and acquaintances, especially those I met while travelling in the Southeast, would remark that it was just as well that I already had a significant other, since I wouldn’t find many potential partners in Rio Grande do Sul—insinuating widely prevalent male homosexual practice. Malathronas (2003:463), who is gay, records similar reactions from Brazilians across the country. Pelotas, another city in Rio Grande do Sul, is particularly famous in this regard.
feijoada, which is considered the national dish of Brazil, the South is renowned for churrasco, meat rubbed with rock salt and grilled on a skewer over a flame.

The characteristics mentioned above recall similar but better-known expressions in Uruguay and Argentina. Porto Alegre is notable for its proximity to these nations, and celebrates this relationship by calling itself the capital of Mercosul. But regional parallels did not derive from such relatively recent economic ties. Rio Grande do Sul was not colonized by Europeans until 1626, and then not by the Portuguese, but Spanish-speaking Jesuits who founded missions in an area that today includes parts of both RS and Argentina. During colonial times, the entire region lay far from centers of concern to both the Spanish and Portuguese colonizers (Clayton and Conniff 1999). By the time the area was officially ceded to the Portuguese, in the Treaty of Madrid in 1750 (Schenkel 1999:23), shared cultural forms had developed; throughout the region, cattle-herding and the production of dried beef were economic mainstays until at least the 1840s (Clayton and Conniff 1999:89). Thus it was only as a result of political boundary-drawing that the figure of the gaúcho came to symbolize a transnational cultural form.

The shared name for this icon, on either side of a line ostensibly separating two nations that speak different languages, is emblematic of other linguistic similarities. Whereas in most of the rest of Brazil the pronoun “you” can be expressed either formally, by o senhor (or a senhora), or informally by você, in Rio Grande do Sul among friends “you” is always expressed by tu, just as in Spanish.⁷ Porto Alegrenses were notably more familiar with Spanish than their

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⁷ Phonetically, that is. In Brazilian Portuguese, both você and o senhor (2nd person pronouns), as well as ele and ela (he and she, or the 3rd person pronouns) take the same conjugated forms of verbs. Although different verb endings exist for use with tu, in Porto Alegre tu is usually paired with verbs conjugated to agree with você. Thus, instead of the Spanish, “Tú estás bien?” Porto Alegrenses typically say, “Tu (es)tá bem?” Incidentally though, I frequently heard people originally from the extreme south of the state employ the tu form of verbs, a clear influence from Spanish.
counterparts in the Southeast region, and it was not uncommon to hear Gaúchos greet each other by saying, “Buenas,” borrowed from Spanish. While no one would mistake the Gaúcho accent for Spanish, no Brazilian could mistake it for being from anywhere but Rio Grande do Sul, due to its characteristic sing-song quality and regional vocabulary.

Rio Grande do Sul’s “differentness” has, at times and in certain quarters, been stridently separatist. In 1836, its desire for greater political autonomy prompted its secession from Brazil and the declaration of the independence of the Rio-Grandense Republic. The ensuing War of the Farrapos “taxed the resources of the empire” (Clayton and Conniff 1999:91) until 1845. Though members of the still-extant independence movement are not much in evidence in the capital, the armed conflict is far from being repudiated. It is commemorated in Porto Alegre with a festival that celebrates the “traditional” lifestyle of the Gaúchos. The Semana Farroupilha includes parades, livestock shows, rodeo events, storytelling, and competitions in everything from taxidermy to handicrafts to folk dance. In 2011, a million people participated, according to official estimates. The heart of the festival, though, is a two week-long, government-sanctioned, old-time cowboy style, mass camp-out that happens in September along the bank of the Guaíba River. The most committed, including many who hail from the interior of the state, arrive with the materials to build small wooden shelters. They cook meat over wood fires, wear traditional clothing, drink chimarrão and participate in events as competitors, vendors, and spectators. While some inhabitants of the capital denigrate these cultural expressions, they are widely valued and exert an undeniable and highly visible influence on the identity of the city. In comparison with the ideal of “Brazilianess” marketed abroad, and held by many non-Southerners themselves, Porto Alegre presents an undeniable, indelible contrast.

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8 I experienced this lack of familiarity, for example, in the city of Rio de Janeiro, which I visited several times, and the state of Espírito Santo, where I did previous fieldwork.
Difference: Politics

This “difference” also extends to politics. Even after the attempted secession (a testament to perceived political difference if ever there was one), Bethell (2000:25) notes that the confluence of Auguste Comte’s positivism and “gaucho frontier traditions” produced a centralized structure in the ruling party in RS that was at odds with prevailing conditions in the rest of Brazil. In the first half of the 20th century, Governors Borges de Medeiros and Vargas (who would later become President, both through coup and electoral victory) carried this distinctiveness forward, in their reliance on a stronger, more activist role for government in both economic development and social organization than was the case in most of Brazil’s other states (Bethell 2000:25). The corporatist, authoritarian streak in the South came to impact the entire nation, not only through Vargas’s administrations, but also in the numerous military leaders from RS that served as heads of state during the 1964-1985 dictatorship (e.g., Castelo Branco, Costa e Silva, Médici, Giesel, see Skidmore 1999).

Rio Grande do Sul’s political legacy is not solely centralization and repression, however. Leonel Brizola, for instance, was a Gaúcho politician famous for his opposition to military rule, and Giesel was instrumental in facilitating the period Brazilians call *abertura* (literally, “opening,”), which brought the dictatorship to an end (Skidmore 1999). In Porto Alegre specifically “there has been a long tradition of the [Catholic] Church having progressive Bishops who were sympathetic to issues of human rights and social justice” (Murray et al 2011:947). In addition, in the first the direct municipal elections after the dictatorship, the *Partido dos Trabalhadores* (PT), or Workers’ Party, won the mayorship in Porto Alegre. Reflecting the political moment and its core ideology, the PT’s democratic socialist agenda emphasized “the

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10 It is from this political party, founded in São Paulo in 1980, that recent President Luís Inácio Lula da Silva (administration 2002-2010) and the current President, Dilma Rousseff, both hail.
decentralization of power, government accountability to autonomous social movements, and a reversal of priorities away from elite groups toward the poor and disadvantaged" (Abers 1996:37). The party controlled the city’s executive branch (the mayor’s office is called the Prefeitura) for 16 years, from 1989 to 2005.

The PT’s tenure produced the achievements for which Porto Alegre is best known in academic circles: Participatory Budgeting and the World Social Forum. Participatory budgeting began in Porto Alegre in 1989, and immediately confronted serious challenges (Abers 1996), among them the logistics of including impoverished neighborhoods in city government. Given that “The poor are used to what might be called cultura do favor [“culture of favor”], in which important acts of political citizenship are decided through personal networks instead of open, public channels” (Avritzer 2010:173),11 the debate among scholars about the role of clientelistic politics in the process is ongoing (see also Boaventura de Sousa Santos 1998; Souza 2001; Baiocchi 2003). The World Social Forum, which features Outro Mundo É Possível (“Another World Is Possible”) as its slogan, is a gathering of civil society groups that occurs in parallel to the World Economic Forum. It was held for the first time in 2001, in Porto Alegre; the municipal (PT) government was one of the sponsors (Hammond 2003). The PT’s long administration of the city also impacted the municipal response to HIV/AIDS, but in order to better understand the actions that were taken, as well as the parameters within which those decisions were made, an overview of the epidemic is necessary.

HIV/AIDS in Porto Alegre: Epidemiology Present and Past

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11 This is, according to many Brazilianists, true not only for Porto Alegre, but for the whole nation: “Historically, elections in Brazil had more to do with public demonstrations of personal loyalties, the offer and acceptance of patronage, the reduction of social (and regional) tensions and conflict, and, above all, control of a patrimonial state and the use of public power for private interests without resort to violence than with the exercise of power by the people in choosing and bringing to account those who govern them” (Bethell 2000:3).
Although most studies published in English on HIV/AIDS in Brazil are based in the Southeast and the Northeast regions (specifically São Paulo, Rio de Janeiro, and Salvador), this research was conducted in Porto Alegre, partially due to the city’s role in the notable state-level AIDS epidemic. In fact, according to the former director of Porto Alegre’s municipal AIDS program, due to the size of the epidemic in Porto Alegre, “Rio Grande do Sul has always been the state with the third greatest number of cases [of AIDS], even though it’s not the third most populous state” (interview, 20 June 2007). The epidemic is an unfortunate reinforcement of a contention I heard from many Gaúchos that Porto Alegre is the “third city” of Brazil, after São Paulo and Rio.

As of May 2011, the city’s epidemiological surveillance team had documented 1,390 incident cases of AIDS in the city in 2010 (in Porto Alegre, as is the case throughout Brazil, AIDS, not HIV, is the notifiable diagnosis), which translates to an incidence rate of 98.59 per 100,000. This is even higher than the ten-year (2001-2010) average of 90.58 cases per 100,000 that earned Porto Alegre the unenviable top ranking in AIDS incidence among Brazilian municipalities (Stella, Qualisoni, and Moysin 2011:2), and much higher than the state, regional, and national rates of 39.1, 29.1, and 19.6 per 100,000, respectively (Ministério da Saúde 2012:3). Unfortunately, it’s not appreciably higher than data from the previous several years (which are considered more complete), as can be seen in the figure below (from Stella et al. 2011:2).
While the 59,527 AIDS cases diagnosed since the beginning of the epidemic through 2010 in Rio Grande do Sul are dwarfed by the number of cumulative diagnoses made in São Paulo (207,279), and Rio de Janeiro (85,152) over the same period, the proportion of residents affected in the former state is greater (Ministério da Saúde 2012:4). From 1991-2000, RS reported the third highest accumulated incidence per 10,000 inhabitants in the nation, at 39.5 (Rodriguez-Junior and Castilho 2004:313). Then, in virtually every year since AIDS surveillance became a municipal responsibility, in 2001, RS has led all Brazilian states in standardized measures of incidence.\footnote{Only Rio de Janeiro posted a higher incidence rate, in 2004 (Ministério da Saúde 2012:3).}

As noted previously, Porto Alegre drives this trend; hence, the contours of the state epidemic largely reflect those in the capital city. As of 2010, municipal surveillance records the most common mode of transmission as heterosexual contact, with the male : female ratio of new infections standing at 1.5 : 1. Vertical transmission accounts for less than 5% of incident cases.
Individuals classified as preto or pardo (ethnic group terms that translate as “Black” and “mixed;” recall that these two categories together make up around 20% of the city’s population) figured disproportionately in new diagnoses, with the average (for 2001-2010) for men being 26.9%, while for women it was 32.7% (Stella et al. 2011:2). With regard to formal education, “the greatest concentration of AIDS occurred among those had no more than eight years of schooling” (Stella et al. 2011:3).

This has not always been the picture of AIDS in RS. As happened in the U.S., AIDS in Brazil made its debut in large cities. The first case was diagnosed in São Paulo in 1981 or 1982. Porto Alegre was affected shortly thereafter, in 1983. The epidemiological profile of those initially infected was largely consonant with that found in many other places: male, living in a large city, between 30 and 39 years old, with some form of post-secondary education (and hence relatively affluent), and infected through male-to-male (MSM) sexual contact. In fact, for a decade transmission via MSM was associated with more than 50% of new infections each year among men in RS (CGVS-POA N.d.:6; SES-RS N.d.b: 2, 3, 5, 6), only being displaced by injection drug use (IDU) as the most common route of infection in 1994.

In a “middle period” of the state’s epidemic, particularly among men, IDU played a prominent role. After the turn of the millennium, however, it diminished substantially. While IDU was identified as the mode of transmission in 32.2% of incident cases in 2001, that percentage dropped until it reached approximately 22% in 2005 (SES-RS N.d.b:4, 3). Although reported incidence of AIDS was lower overall in 2005, had male IDU-related transmission persisted at 2001 levels, 443.2 incident cases would have been expected; the observed incidence was 307. From 2001-2005, the number of new cases attributed to IDU among women also

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13 The date given depends on the source consulted. The General Coordination of Health Surveillance of Porto Alegre (CGVS-POA) gives the former date; the Brazilian Ministry of Health gives the latter.
decreased (from 138 to 83). If IDU-related transmission had occurred at the same rate in 2005 as in 2001, the expected number of diagnoses attributable to IDU would have been 121.4; the documented cases represent only 66% of this total.

It is difficult to ascribe a cause to this reduction in IDU-related AIDS cases. While harm-reduction efforts likely played a role (see below), given the complexity of epidemics like HIV, a former director of Porto Alegre’s municipal AIDS program explained that it was probably also a result of the arrival of crack on the city’s drug scene. This was initially almost welcomed in epidemiologically-minded circles, since fewer people would be shooting up (interviews, 20 June 2007; 29 April 2009). However, as in other contexts, less IDU did not translate to a reduction in AIDS transmission overall: “Studies demonstrate an association between the use of non-injection drugs, especially crack cocaine, with increased risky sexual activity and a concomitant increase in HIV infection. As drug addiction increases, so does women’s reliance on exchanges of sex for money or drugs” (Romero-Daza et al. 1999:108; see also Sterk and Elifson 2000). As this dynamic became apparent, an effort was made to target the city’s population of female drug users for the distribution of condoms, but the staff at surveillance unit soon discovered that such actions would not eliminate HIV transmission among crack users. Given their poverty, crack addicts were selling the condoms, and still trading unprotected sex for drugs (interview, 20 June 2007).

Thus, by the mid-1990s, the processes of heterosexualization, feminization, and pauperization, noted in the Brazilian epidemic as a whole (see below; also Berkman et al. 2005:1162), began to change the demographics of Gaúcho seropositivity. Among men, heterosexual transmission surpassed IDU as the most commonly identified mode of transmission in 2002; it has remained so ever since. With the exception of 1988, heterosexual transmission
has always been the most important identified mode of infection for women (SES-RS N.d.b: 4), who have become infected in increasing numbers. The sex ratio among the newly infected fell precipitously, from 72:1 (men to women) when the first female AIDS case was discovered in RS in 1986, to 5:1 in 1991 (SES-RS N.d.b: 2). While the national epidemic has reached a sex ratio of 1.5:1 (UNAIDS 2007), Gaúchas in 2005 came even closer to closing the gender gap, becoming infected at a ratio of 1.35:1 (SES-RS N.d.b: 2). In addition, in some of Porto Alegre’s health districts (including the one that is home to the recruitment site for this study) nearly equal numbers of men and women were diagnosed in 2010 (Stella et al. 2011:3).

![AIDS Incidence by Exposure Category Among Men in Rio Grande do Sul](image)

Figure 2.2: AIDS Incidence, Men  (Figure Data from SES-RS N.d.b)
Figure 2.3: AIDS Incidence, Women  (Figure Data from SES-RS N.d.b)

The pauperization of the epidemic is typically abstracted from the “years of education completed” variable on the notification form for AIDS. Until 1990, in RS, when educational attainment was recorded at all, it was most common to find some form of post-secondary education. Then, for nearly a decade, the largest percentage of newly infected individuals had not completed the equivalent of US elementary school. Since approximately the turn of the millennium, the average (formal) educational attainment among the incident population is now between the equivalent of U.S. 5th and 8th grade (SES-RS N.d.b:6). Smaller, but roughly equal, proportions either graduated from high school or did not finish elementary school (SES-RS N.d.b: 6). Those with post-secondary education lag far behind, not having accounted for even 10% of new infections since 1995.

Another way of approaching pauperization is through spatial analysis. Analysts at the municipal health surveillance office (Coordenadoria Geral de Vigilância da Saúde-Porto Alegre, CGVS-POA) use a Geographic Information Systems program designed for their
organization to geocode each patient’s address at time of AIDS notification. Barcellos et al. mapped the prevalence of HIV among pregnant women in the city, and compared it to areas identified by the IBGE (Brazilian Institute of Geography and Statistics) as *favelas* (called *vilas* in Porto Alegre), or shantytowns. Although the relationship is not direct, “In general, areas with high prevalence of HIV among pregnant women are close to *favelas*” (Barcellos et al. 2006:93), which the authors see as confirming the pauperization observed in other studies (Bastos and Szwarcwald 2000).

Spatial analysis has also been used to document the spread of the epidemic. Although HIV has not yet become common in rural communities, it is present throughout the state, having spread from Porto Alegre to the secondary cities along the border and the coast. This has led to concerns about interiorization (CGVS-POA N.d.:1). In other trends, incident cases are increasingly being found among older cohorts. Since 2000, growth in the percentage of cases found among the 40-49, 50-59, 60-69, and 70+ age groups is unmistakable (SES-RS N.d.b:5).

**A Word on Epistemology and Epidemiology**

Two potentially troublesome transitions have been elided in the reporting of surveillance data above. The first has to do with the municipalization of AIDS surveillance in 2001. Given this change, alterations observed in the data from roughly 2000 to 2002 may be artifacts of differing surveillance methodologies rather than a reflection of a changing epidemiological reality. The second involves a switch in the software used to report notifications that occurred in 2007; some of the data from the older database were not transferred, complicating comparisons (Stella et al. 2011:3). This brings up the fundamental uncertainty inherent in surveillance data: what the numbers tell us is always dependent on how and what we consider important enough to count. As such, the epidemic may differ significantly from our depiction of it.
The early identification of specific “risk groups” is an instructive example. Just as in the U. S., in Brazil such ideas had a profound influence on perceptions of who was at risk, instilling a false sense of security in many (CGVS-POA N.d.). The first woman wasn’t diagnosed with AIDS in RS until 1986, and women did not constitute more than 10% of new infections until 1990 (SES-RS N.d.b: 2), but very quickly thereafter, as mentioned before, the sex ratio of infected individuals began to equalize. This should prompt us to ask: was the rapid growth in infections among women something that happened “in the real world” or a phenomenon produced by data collection? “Feminization” of the epidemic in Brazil is due to many factors, but the early absence of prevention efforts targeting women and the later realization that women actually were at risk, and hence should be tested, probably both played a role. Although some might assert that our knowledge of the virus has taken us beyond such considerations, similar issues can be raised with regard to the surge in incident infections among more elderly cohorts.

Unknown or uncollected information is another problem. For example, prior to 1990, data about educational attainment was collected for less than half of newly infected individuals each year. And until 1992, the largest proportion of AIDS cases among women was ascribed to “unknown” modes of transmission (SES-RS N.d.b:6, 4). Some omissions even lead one to suspect what Fassin has called “an official policy of selective blindness” (Fassin 2004:211). For instance, it was less than a decade ago, in response to demands from the Black Movement, that those filling out the notification form for AIDS were explicitly directed to fill in the check-boxes for race/ethnicity (interview, 20 June 2007). Essentially twenty years of the epidemic passed without any systematic attempt to deal with this fundamental aspect of social reality, allowing the SES to contend that an “evaluation of the proportional distribution of cases by race is impossible, given the inconsistency of those data on notification forms” (SES-RS N.d.a:9).
More recently, the municipal surveillance office has attempted to “rescue” unreported cases by cross-referencing AIDS notifications with databases that include death certificates, hospitalizations, and laboratory exams. While this has resulted in reducing underreporting, these other sources of data often omit race/ethnicity, contributing to an increase in “unknown” data in this category (Stella et al. 2011:2). Race is an incredibly complicated issue in Brazil, and certainly enmeshed in the biosocial phenomenon of HIV/AIDS. That relationship, however, is likely neither direct nor simple. Not collecting these data does not eliminate the relationship; it simply makes it impossible to study.

On the other hand, since 2001, when the task of epidemiological surveillance for HIV/AIDS was assumed by the municipality, it has been conducted actively, unlike some other major cities in Brazil (interview, 20 June 2007). A representative of the municipal surveillance office of Porto Alegre (Coordenadoria Geral de Vigilância da Saúde-Porto Alegre, CGVS) visits hospitals daily in search of cases of AIDS, deaths from AIDS, and HIV-diagnoses in pregnant women, all of which are obligatory notifications. In addition, each month CGVS checks its database against that of the program that, administered by the City Health Department, distributes infant formula to HIV-positive mothers.

Overall, the difficulty of controlling the epidemic is perplexing because Porto Alegre is in one of the wealthier regions of Brazil, with some of the best health infrastructure, and, at least on paper, implemented evidence-based public health policies to prevent the spread of HIV/AIDS. They publicized HIV prevention through informational campaigns; made free male and female condoms available to inhabitants through the public health system; created free, anonymous HIV-testing services with pre- and post-test counseling (Biehl 2007:259); instituted HIV testing as a routine part of prenatal care (Bergenström and Sherr 2000); implemented international
guidelines regarding the use of AZT and the prohibition of breastfeeding for the prevention of maternal-to-child transmission (MTCT) (Kreitchmann et al 2004); provided a six-month post-partum supply of free formula to HIV-positive mothers (Kreitchmann et al 2004); offered free, specialized care to HIV-positive individuals, including mental health care; and integrated their harm reduction program (needle exchange) with those other services in order not to marginalize IDU (SES-RS N.d.c, accessed 9/13/08).14

Given these commitments, Porto Alegre’s AIDS incidence rate provokes debate among experts. An explanation offered by public health professionals is that rigorous municipal surveillance makes incidence look higher than in other places. They also argue that under-reporting is minimized because AIDS patients in Porto Alegre are entitled to assistance (free and specialized medical treatment, free formula for HIV-positive mothers, free in-city public transportation, etc.) that is unavailable or more difficult to obtain in other places. It is said to be a regular occurrence, for instance, for patients to come to the municipal surveillance office themselves to make sure their case has been registered (interview, 26 June 2007).15 While these factors should not be discounted, it is also surely the case that not every HIV-related intervention achieves its stated goals. For now, the debate continues.

In these first two sections, I have offered an abbreviated and highly selective description of the cultural and epidemiological context in which the HIV-serodiscordant couples in this

14 This list derives from scholarly publications, the RS State Health Secretariat website, and my own investigations, from May-July 2007, March-December 2009, and January-July 2010. As it is not included elsewhere, the 2007 fieldwork consisted of nine unstructured interviews with biomedical and public health practitioners, each lasting between 30 minutes and 3 hours (eight of which were face-to-face, and one over email), as well as a semi-structured, face-to-face interview that lasted two hours with directors of a non-governmental organization (NGO) involved in the AIDS movement. Finally participant observation was conducted in support groups and treatment centers for HIV-positive patients.

15 In fact, in the approximately six hours I spent at the CGVS-PA, I saw this happen. A thin, frail, shaky woman and her younger companion—a son, it seemed—arrived, requesting official documentation of her serostatus in order to obtain benefits.
research live. However, there are national and international forces at play as well that, while inevitably refracted by Porto Alegre’s position (as a Brazilian city, at a particular historical moment), also impact them. The next section therefore traces the trajectory of HIV/AIDS in Brazil, focusing on epidemiology and history.

**HIV/AIDS in Brazil: National Epidemic and Policy**

Brazil has the largest HIV/AIDS epidemic in Latin America. The most accurate official 2007 count puts the cumulative number of AIDS cases (1980-2006) at 461,202 (PN-DST/Aids 2007a:15). There were 34,480 incident cases of AIDS in 2008; the incidence rate was 18.2 per 100,000 (CNAIDS 2010:13). UNAIDS estimates that there were 630,000 individuals between the ages of 15 and 49 living with HIV in Brazil in 2006 (CNAIDS 2010:13). That number, as large as it is, represents just a fraction of the epidemic many people predicted the country would be facing. In 1990, the World Bank warned that, in the absence of an effective national intervention, 1.2 million Brazilians would be HIV-positive by the year 2000 (Berkman et al 2005:1163).

That this has not come to pass can be considered a major public health achievement—but it is no accident. Even as the World Bank was emphasizing the need for state intervention in the epidemic, the Brazilians were in the process of crafting what is now named the *Departamento de DST, Aids e Hepatites Virais*\(^\text{16}\) (Department of STDs, AIDS, and Viral Hepatitis), but still often called the “National Program.”\(^\text{17}\) Though some of its policies were initially controversial, this

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\(^{16}\) Brazilians adopted the English acronym AIDS into their language as a word, therefore it is not written with all capital letters.

\(^{17}\) This is a hold-over from the previous name: the *Programa Nacional das DST/Aids*, or the National Program for STDs and HIV/AIDS. Throughout this text, “*Divisão Nacional de DST e Aids*” (the original name for the entity), “PN-DST/Aids,” “National Program,” “Department” and “DDST/Aids/HV” are all used, depending on the time period under discussion.
program of integrated prevention and treatment has been recognized as “best practice” for
developing countries worldwide (UNAIDS 2007).

The most frequently invoked explanation for Brazil’s impressive response to the
HIV/AIDS epidemic is historical in nature. It revolves around a fortuitous coincidence: that the
political culture prevalent in Brazil at the moment HIV/AIDS appeared on the national scene was
concerned with citizenship, solidarity, and human rights (Berkman et al. 2005:1163; Biehl 2007;
see also Holston 2008). The nuances of this story (particularly with regard to neoliberalism,
public health spending, and international political economy) are only tangentially relevant to the
data reported in this dissertation; hence only a brief summary need be explored here (but I urge
interested readers to consult, for example, Larvie 1997; Biehl 2007).

The early 1980s saw the virtually concurrent arrival of HIV/AIDS and abertura, the
structured and gradual transition from the military dictatorship that ruled the country for more
than two decades (1964-1985) to a civilian government (Skidmore 1999). As direct state
elections drew near in 1982, many civil society groups organized to press their demands
(Barroso 1991; PN-DST/Aids 2005a). Of particular salience here are two such groups, both
largely concentrated in the Southeast region, where opposition to the dictatorship had been
strong. First, a movimento de reforma sanitária, or “sanitary reform movement,” motivated by
the ideal of health as a human right and convinced of the governmental responsibility to
guarantee citizens’ access to that right, gained power in various branches of local public health
systems. Second, a gay (rights) movement had taken shape, including multiple organizations,
new venues for sociality, and a newspaper (Terto Jr. 2000:63-64).

In the midst of this political effervescence, Brazil’s first AIDS case, a man from São
Paulo who had died in 1980, was (retroactively) diagnosed; ten more cases were diagnosed that
year (PN-DST/Aids 2007b:18, 19). It was in response to pressure from gay and public health activists that in 1983 the São Paulo State Health Secretariat instituted the first AIDS control program in all of Brazil, followed by a similar program in Rio de Janeiro (Terto Jr. 2000:65; Berkman et al. 2005:1165-1166). Shortly thereafter, those states saw the founding of two of the first non-governmental organizations (NGOs) dedicated to the fight against AIDS in Latin America (Berkman 2005:1166, PN-DST/Aids 2007b).

However, it was not until 1986—four years and 739 cases after AIDS was first diagnosed in Brazil (PN-DST/Aids 2007b)—that the federal government established the National Division of STDs and AIDS (Divisão Nacional de DST e Aids), which later became the Programa. The first HIV Testing and Counseling Center (Centro de Orientação e Apoio Sorológica, COAS) was founded in Porto Alegre the following year. Sean Patrick Larvie suggests (1997) that the hesitation in allocating resources to fight the epidemic stemmed from ambivalence about the plight of the populations HIV/AIDS first affected. As in the U.S., AIDS originally most heavily affected men who have sex with men (MSM), and suffering from the disease was seen as a mark of having transgressed Brazil’s strongly heteronormative social order (Rebhun 1999, Parker 1987). Although the DDST/Aids/HV is at pains to demonstrate its sensitivity now (see PN-DST/Aids 2007a), the Brazilian government initially employed the same early “risk groups” the U. S. did: hemophiliacs, homosexuals, injection drug users, and commercial sex workers (CGVS N.d.), with the same stigmatizing results.

For years, São Paulo indisputably remained the epicenter of HIV/AIDS in Brazil, with Rio de Janeiro a distant second. From 1980-1992, state of São Paulo recorded 28,493 cases of AIDS; the number of recorded cases in Rio de Janeiro was 9,235 (PN-DST/Aids 2005b:26). The

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18 Indeed, Veriano Terto Jr. (2002:153) argues that MSM were and continue to be so associated with HIV/AIDS that “gay health” is often reduced to the results of an HIV test.
heavy representation of the Southeast region in the epidemic is shown in the standardized measure of incidence of AIDS cases per 100,000. In 1993, at a time when the epidemic had become more generalized, the Southeast recorded a regional incidence of 20.5 per 100,000 (led by São Paulo at 27.6). By contrast, the South, which had not yet catapulted to the dominance discussed in the previous section, recorded the next-highest incidence rate: 10.1 AIDS cases per 100,000 inhabitants (PN-DST/Aids 2005b:27).

A pivotal moment in the history of Brazil’s epidemic occurred in 1988, when the new Constitution created SUS (Sistema Único de Saúde), Brazil’s national health care system that promises free and universal medical care. According to statements made by officials at the time, the process was guided by three principles: institutional unification, decentralization, and democratization. This meant that fewer Federal Ministries would be responsible for the nation’s health; policy implementation would occur at state or local levels; and service provision would be “free…to all citizens” (de Macedo Rodrigues 1988:230). Civil society, so important in the establishment of SUS, continued to have, and be recognized by officials as having, an important and positive role in the form of “voluntary organizations,” (Cordeiro 1988, Larvie 1997), a role it retains to this day (Biehl 2005b:254).

The 1990s brought other significant events. In 1991 the process for acquiring and distributing antiretroviral medication (the drugs used to treat AIDS, herein ARVs) via SUS began, and the following year saw the first national HIV/AIDS prevention campaign (PN-...
In 1994 Brazil signed the first of several loan agreements with the World Bank, designed to finance efforts to control the epidemic (PN-DST/Aids 2005a). The focus was largely on prevention (Larvie 1997:99) because, at the time, international health experts considered treating diseases like HIV and TB in developing country contexts to be prohibitively expensive (Biehl 2007:3, Kidder 2003). Thus it was a breathtaking assertion of national will when, over the objections of such august bodies as the World Bank and the WHO, the Federal Legislative Assembly passed “Law 9,313 of 13 November 1996.” This law guarantees the right to ARV treatment, and stipulates that it should be distributed free, to all in need, exclusively through the public health system (PN-DST/Aids 2007a; PN-DST/Aids 2005a). As has been acknowledged by Brazil, this law is “firmly anchored in the broader concept of Human Rights and formally guaranteed by the [SUS],” as outlined in the 1988 Brazilian Constitution (CNAIDS 2010:11).

In 1996 there were 24,536 officially notified incident AIDS cases in Brazil, an incidence rate of 15.6 per 100,000 (PN-DST/Aids 2007b:15, 16). It was around this time that PN-DST/Aids began to discern various trends in the epidemic: interiorization (diagnoses being made not only in the large cities, but also in smaller cities and towns, and even in rural areas), feminization (increasing incidence among women), heterosexualization (because women were most frequently infected via heterosexual contact), and pauperization (incident infections becoming concentrated among poorer sectors of society). These trends have persisted over time, and catalyzed the Brazilian tendency to analyze their epidemic through the lens of social inequality (PN-DST/Aids 2007a, Barcellos et al. 2006:93, Bastos and Szwarcwald 2000, Berkman et al. 2005, Biehl 2007, Chequer 1998, Figueiredo and Ayres 2002). This analysis led to the creation of a “Civil Society and Human Rights (SCDH) department of the National

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20 Full text of the law is also available at http://www.aids.gov.br/pagina/leis_decretos_medicamentos
Program, NAP]. SCDH was created in 1997 as one of the six departments of the NAP with the goal of facilitating a direct link between the government and [people living with HIV/AIDS] to strengthen NAP’s actions focused on human rights, AIDS, and social inclusion” (Murray at al 2011:949). That the State, through the National Program, conceived of its work in relation to HIV-seropositive people as an expression of “rights” is clearly evidenced by such initiatives.

The rest of the story, as it tends to be told, features Brazil as a popular demand-driven success story, in terms of upholding human rights, controlling the spread of HIV/AIDS, and in facing down the international pharmaceutical industry. The number of incident cases of AIDS as well as the incidence per 100,000 leveled off in Brazil and in 2006 had declined to 18,879 officially notified incident cases, or 10.1 cases per 100,000 (PN-DST/Aids 2007b:14, 16). This reduction is usually attributed to the pioneering insistence on integrating HIV prevention, free ARV treatment, and medical care—and delivering it through the public health system. This is widely applauded, not only by Brazilian citizens, and not solely in terms of social justice. From an infectious disease standpoint, HIV-positive individuals on effective therapy often have undetectable viral loads, limiting the potential for transmission. Indeed, by 2000, UNAIDS had named the PN-DST/Aids as “best practice” in the developing world, and in 2003 Brazil was awarded U.S. $1 million from the Bill and Melinda Gates Foundation in recognition of its success (PN-DST/Aids 2005a, Berkman et al. 2005, Biehl 2007:8).

Given such success (and acclaim), Brazil was heavily invested in the continuation of the National Program. And yet, in the same year that the PN-DST/Aids was recognized by UNAIDS, then-Health Minister José Serra asserted that “In spite of the national production of generics, prices of patented drugs were seriously jeopardizing the sustainability of the ARV rollout” (Biehl 2007:77). This situation led Brazil to take a prominent role in drafting the Doha
Declaration of 2001 on Trade-Related Intellectual Property Rights and Public Health. In it, developing countries reserved the right to break patents on medication in the service of public health. Brazil itself has repeatedly invoked Doha, threatening to issue compulsory licenses for medications it deems too expensive. The denouement to these threats (e.g., in 2001, 2002, and 2006,) typically includes negotiations with the producers, and agreement on a mutually acceptable price (PN-DST/Aids 2005a, Biehl 2007:91), although Brazil has issued compulsory licenses when this *pax pharmaceutica* breaks down (e.g., 2007). With this, Brazil succeeded in positioning itself along with Thailand, as a leader of developing countries’ ongoing struggle with pharmaceutical companies.

The previous section has documented major events in the history of Brazil’s forward-thinking response to HIV/AIDS, emphasizing that this cannot be understood without reference to civil society mobilization around democratization, and the ascendancy of a particular vision of public health in the 1980s. At that time, notions of citizenship were in flux and fiercely contested (Holston 2008); from these debates a right-based approach to health emerged and was enshrined in the nation’s new Constitution, which chartered the creation of SUS. This approach is the foundational and necessary condition from which state action on HIV/AIDS flows. National and institutional-level commitments to the ideal of “health as a human right” are not perfectly executed or effective, but have produced impressive results and give rise to legal and material structures for confronting the epidemic. In order to better understand how these national-level dynamics play out in the lives of HIV-serodiscordant couples in Porto Alegre, a return to considering more local context is in order.
SUS Response to HIV/AIDS in Porto Alegre

As previously mentioned, SUS was created in 1988. It was a major achievement for those within the sanitary reform movement who believed that health as a human right should be “guaranteed through social and economic policies that seek to reduce the threat of sickness and disease and offer universal egalitarian access to actions and services designed to promote, protect and recuperate [health]” (CNAIDS 2010:11). The stated goal of the system is to “change the situation of inequality in the population’s access to Health.”21 The values of universality, equality, and integralty mean that all Brazilians should have access to the level of care they require, free of charge. But this simple mandate is challenging to execute. SUS has adopted a strategy of “municipalization,” which designates cities as the primary entity responsible for delivering health services to the population, with state and Federal levels of government fulfilling complementary functions (setting guidelines, making policy, coordinating between cities and regions, channeling resources, etc., see Ministério da Saúde 2006:8-22). This arrangement was formalized in a 2001 agreement, called the Normas Operacionais de Assistência (or NOAS-SUS), and further elaborated in the 2006 Pacto da Saúde (Health Pact). These general guidelines are to be revisited in light of epidemiological trends and current institutional capabilities during annual planning meetings (PN-DST/Aids N.d.).

The system is designed so that the point of entry for patients is ideally a primary care location close to their residence. This is called either a Unidade Básica da Saúde (UBS, Basic Health Unit) or Estratégia Saúde da Família (ESF, Family Health Strategy). For the purposes of this research, the contrasts between these two types of neighborhood health stations are less important than what they have in common (but for an explanation of the differences, see Escorel et al. 2007; Ministério da Saúde 2006:22). Both are intended to offer primary care to fewer than

5,000 residents that live in the vicinity of the installations. The composition of the staff at these small clinics can be interdisciplinary and frequently includes Community Health Workers (for more on their role, see Pinto et al. 2012); they are supposed to develop an understanding of the health conditions that most frequently affect the families and individuals living in their catchment area. During the fieldwork period for this research, there were 117 of these stations in various neighborhoods around Porto Alegre.

When a patient presents with a medical issue that demands more specialized care than these units can provide, that patient is referred to a service equipped to handle such cases. Often, this is a “Municipal Health Center,” of which there are seven in Porto Alegre. As they do not all offer an identical complement of medical specialties, referrals outside of one’s “home district” are often necessary, but the idea is to keep patients at the most “local” level in this hierarchical health network that meets their needs. Only patients requiring “high complexity” services are typically referred to hospitals, for example. Of particular interest to health authorities is to keep as many patients out of the emergency departments (EDs) at area hospitals as possible. The frequent news reports on the Porto Alegre’s overflowing EDs, and my own observations at two of them, however, attest that this objective has not yet been achieved (fieldnotes, 20 October 2009).

In part this may reflect the fact that systems evolve over time, and extant infrastructure (and habit of use) was built in response to past needs, and administered through potentially different systems. HIV/AIDS care in Porto Alegre provides a clear example. In theory, each level of the health system has particular responsibilities with regard to HIV, just as they do more generally. The orienting principle of decentralization/municipalization stipulates that municipalities have the duty to provide care to seropositive people, and to make and implement
relevant local policy in response to the epidemic’s local contours. This confers upon them significant discretion in surveillance methods, program planning, the structure of service delivery, and, hence, resource allocation (as demonstrated by the transition between PT and non-PT city administrations in Porto Alegre, discussed above). On the other hand, these decisions are informed by actions taken at the Federal and State level. The Ministry of Health, for example (currently through the DDST/Aids/HV) has the responsibility of setting national policies; designing national prevention campaigns, often via mass media; interfacing with international organizations; monitoring, evaluating, and advising the state and municipal level health secretariats; and disbursing funds. The National Program is also responsible for aggregating state-level data from three separate, national level surveillance systems: SINAN (notifiable diseases), SICLOM (control system for ARVs), and SISCEL (CD4 and viral load lab results).

The way most seropositive people, however, experience Brazil’s HIV/AIDS policy is through filling prescriptions for the various medications they may need, and receiving treatment from particular biomedical practitioners. This is where the principle of decentralization has a fundamental impact on HIV/AIDS care, and helps explain not only continuities, but also contrasts in the experiences of patients in different locales. In terms of pharmaceuticals, each level of the system is responsible for procuring certain classes of drugs. So-called “strategic” medicines are those included in specific health programs, like Women’s Health (for more on this program, see for example Giffin 2002) or the HIV/AIDS program (hence, this category includes ARVs); these are purchased and distributed by the Federal Ministry of Health. “Exceptional” medicines, “those considered high-cost or for continuous treatment” are the responsibility of state health secretariats. This leaves the municipal level to buy “basic” medicines (Ministério da Saúde 2006:6-9), which are often the ones used for treating opportunistic infections, among other
ailments. It is possible, therefore, for an HIV patient in one place to be able to fill his or her prescription for ARVs (provided by the Federal government), but find that the pharmacy is out of the medicine s/he needs for Gaucher disease (provided by the State), as well as a basic antibiotic for the prevention of opportunistic infections (like Bactrin, provided by the municipality), while another patient in a different location prescribed the same medications has no problem obtaining all three.

Likewise, physical condition, staffing, and other clinic-specific factors vary from place to place. As part of the development of the PN-DST/AIDS, specialized clinics, called Serviço de Atendimento (or Assistência) Especializado em DST/Aids (SAE-DST/Aids, or, more commonly, simply SAE), were established to provide treatment to people living with HIV/AIDS. Because the provision of health services is now seen as the duty of the city government, these clinics should—theoretically—all be run by municipalities. However, the availability of medical attention for seropositive populations evolved along with the epidemic itself, and pre-dates the concern with municipalization of SUS. Hence, although in theory the division of responsibilities is clear, in practice there is variation. For example, few of the multiple places where an HIV-positive individual can receive treatment in Porto Alegre are managed by the city. Of the six treatment locales I visited during my fieldwork, two were state-administered, one was predominantly Federal, and one was a private entity contracting with the city. Both of the state-administered clinics were ostensibly being “municipalized,” but none of the staff I spoke to there had any idea how long that process would take, what specific changes might be implemented, or how these might impact the daily clinic routine.

Such arcane considerations are important to people “on the ground” chiefly as they articulate with issues of policy-making and finance. Therapeutic contexts attached at diverse
points (Federal, state, municipal) to the health system may be subject to different guidelines; initiatives adopted by Porto Alegre’s health department, for example, would not necessarily be replicated in state-administered clinics. Perhaps more importantly (although with similar possible *de facto* results), they are funded differently, which can lead to dramatically divergent experiences of and options for treatment. For instance, the Federally-supported treatment location—despite being located in a hospital that provided only comparatively basic infrastructure—where I observed and interviewed had a clean (if somewhat spartan) waiting area, modern exam rooms, and offered access to experimental treatments and supplementary services (through internationally-funded research). It was not infrequent for staff and patients there to explicitly and approvingly contrast these conditions to those prevailing at one particular municipal clinic: the site where serodiscordant couple recruitment for this research took place. Although I did not ascertain the basis of most such comments, one female patient in her 30s had an empirical foundation for her evaluation, the content of which did not differ in any substantial way from the others. She had initially been a patient at the municipal clinic, and described it as awful, everything falling to pieces. She continued: “The [patients] there are different, too. Really sick, older—they’re done for. That ton of medicine [they have to take], I didn’t want that. [It’s] because it’s in the *vila*, you know” (observation, 20 October 2009).

While such comments raise many issues, here I merely want to posit that “receiving treatment for HIV/AIDS” is not a uniform experience, even within a relatively circumscribed context like Porto Alegre. Nonetheless, it is in the *vila* mentioned above that the city’s response to the epidemic has taken its most recognized material form. This is partially because, as the site of the oldest—and until 2008, the only—municipal clinic, it had the most direct relationship with the city government. Hence, it is through this site that political will regarding HIV can most
productively be read. The focus on this clinic is also appropriate, given that it served as the primary recruitment site for this study. The following description of the evolution of the clinic and the city’s AIDS policy is informed primarily by fieldwork, although observations and interviews have been triangulated where possible by epidemiologic trends.

The Clinic Context

Neighborhood and Health Center Characteristics

As made clear by the comment reported from the HIV-patient above, the vila in which the oldest municipal clinic is located constitutes part of the clinic’s identity. The first time I took public transportation to reach the clinic, I asked a downtown newspaper vendor which bus lines served that neighborhood. He looked at me and shook his head, saying, “You don’t want to go there.” This sentence, uttered in the city center, to a woman (un)marked by multiple privileged statuses, metaphorically reproduces the vila’s history, remaking the undesirability that brought it into existence in the first place, a product of the urbanization noted at the beginning of this chapter.

Scholars have noted that in Brazilian capitals in the 1950s, “Urban space passed through a process of verticalization and peripheralization” (Monteiro 2007:162; see also Caldeira and Holston 2004; Holston 2008); tall, modernist apartment buildings became common in downtown areas, but low-skilled workers were forced to the outskirts of the growing cities. Thus, the geographic location of the homes of those considered marginais (literally, “marginal,” but with connotations of poor and criminal) became a symbol of their social standing. In Porto Alegre specifically, in 1959 the city legally identified and demarcated 58 neighborhoods, while 40 areas of so-called auto-construção, or “self-constructed housing,” largely home to unskilled workers and migrants from the interior of the state, remained officially unnamed but continued to grow
on the periphery. The neighborhood that today includes the municipal clinic (as well as the homes of two of the participating couples) was one of these very zones of *auto-construção.* Present but excluded from formal (i.e., “respectable”) neighborhood status, at the close of the 1950s the area had no municipal representation; instead, it was “led by an elite group of workers” associated with the Social Security Institute (Monteiro 2007:174). Although the area now has elected representatives, it is still classified by the IBGE as a “subnormal agglomeration” or a shantytown (IBGE 2010). It also retains its association in the popular imagination with marginality.

This historically marginalized area is home to one of the city’s most well-known Municipal Health Centers. With an area of over 15,000 square feet, many residents of Porto Alegre, but especially those who lived in the vicinity, called it simply the *Postão* (literally, “Big [Health] Post”). At the time of this fieldwork it offered a host of medical specialties (for example, physical therapy, speech therapy, children’s health, radiology, tuberculosis treatment, harm reduction and emergency mental health services, among others) as well as housing a UBS and an ED, a public health laboratory, a district pharmacy, and Brazil’s first HIV counseling and testing facility (COAS), in addition to the specialized STD/AIDS clinic.

As of 2009 the physical installations, however, had, generally fallen into a serious state of disrepair. The electrical grid was not capable of powering elevators, much less providing building-wide heat or air conditioning. Broken windows, exposed pipes and air ducts, cracked or missing tiles in the walls and floors were common. In some places on the upper floors, daylight shone through holes in exterior walls big enough to pass a fist through. The dilapidation was not uniform, though. The director of one newly-renovated clinic space joked with me that stepping

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22 Three additional couples lived in areas that likely had very similar histories, although they do not fall specifically within the neighborhood Monteiro (2007) discusses.
through the door was like leaving “the Third World” and entering “the First World.” Conditions at the specialized clinic (hereafter, simply “the clinic”) when I first visited in 2007, as well as when I returned in 2009, were decidedly not of “the First World.” Located in an out-of-the-way corner of the Postão, the clinic looked as though it had seen no updates since its inauguration in 1996.

**Change at the Clinic Over Time**

The clinic’s evolution mirrors the changes in the epidemic, as well as changing political conditions. When it opened, the service it provided was actually primarily adult home care. According to a nurse technician, “We gave everything to patients in those days—beds, mattresses, IV poles, you name it. We would go to their house and do the treatment there. Later, things started changing” (interview, 26 June 2007; also 29 April 2009; 24 August 2009). Home-based care became impractical as the number of patients grew; in addition, the effectiveness of combination therapy meant that fewer patients were home-bound. With longer survival times, pregnancies among HIV-positive women became more common; HIV prevalence among pregnant women in the city’s public pre-natal clinics reached 3.3% by 1997 (Bergenström and Sherr 2000:177). Thus, the focus at the clinic widened to include working with *gestantes-HIV* (HIV-positive pregnant women) to reduce MTCT. One final change that was mentioned by all the biomedical professionals I interviewed at the clinic both in 2007 and 2009 was the so-called pauperization of the epidemic. As poorer and poorer patients became the norm, the kinds of problems the clinic confronts also changed, because, as one practitioner bluntly said, “They really do have absolutely nothing” (interview, 24 August 2009).

Today the clinic offers routine HIV check-ups (which include CD4 and viral load testing) and ARV monitoring, treatment of opportunistic and sexually transmitted infections (including
HTLV), gynecology and prenatal appointments, pediatrics, physical therapy, services of nutritionists and social workers, and psychological counseling (through COAS). An on-site pharmacy dispenses ARVs, as well as select other medications taken by AIDS patients. HIV-positive patients are seen every three months, with the exception of pregnant women, who are seen once a month. Prescriptions are generally written to last until the anticipated date of the next appointment, but must be picked up every month. Patients can make appointments via telephone, and the clinic attempts to hold at least a few slots each day for walk-ins.23 Such frequent and individualized treatment is truly impressive in the context of SUS. Emphasizing the importance of adhering to treatment, social workers make home visits if necessary (Kreitchmann et al. 2004; interview 29 April 2009). About this busca ativa, or “active search,” a nurse technician who participates in the pediatric visits commented, “I think we here in Porto Alegre are the only ones who do it” (interview, 26 June 2007).

This is perhaps a holdover from earlier treatment modalities, and perhaps a legacy of the 16 years (1989 to 2005) of municipal governments dominated by the Partido dos Trabalhadores (PT), which, at least rhetorically, accords high priority to public welfare and social assistance. This inclination toward “activity,” was—in the past—complemented by consistent and dedicated funding of the municipal HIV/AIDS program. Multiple people I interviewed (e.g. interviews, 29 April 2009; 24 August 2009; 21 September 2009) commented, however, that since 2005 the Prefeitura (mayor’s office) had basically dismantled the unit. Though it used to occupy an entire floor of the Municipal Health Center (the same building where the clinic is still located), and number 16 employees, the program itself was relocated to the City Health Department’s central offices, and staff has been reduced by more than 75% (interviews, 26 June 2007; 8 May 2009).

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23 The impact of these practices on degree and ease of access to care was mentioned by nearly everyone I spoke to, and was explicitly contrasted with the procedures used at neighborhood health stations (one has to actually go to the USB/ESF to obtain an appointment).
In addition, the municipal harm reduction program, which began as a small project in response to the city’s IDU-related AIDS cases, was reorganized. It had been decoupled from the AIDS program, from which it previously obtained a good part of its financing for needles and condoms; during 2009-10 it fell under the purview of the under-funded mental health division (interviews, 26 June 2007; 12 August 2009).

Not all of the recent changes are so openly lamented, however. For instance, after years of postponement, in 2008 the city opened a second specialized, municipal, clinic to treat HIV/AIDS and STIs. This unquestionably led to shorter wait-times for initial appointments (interview, 12 August 2009). In addition, on World AIDS Day 2009, also after much delay, the clinic that has been the focus of this discussion moved upstairs from its original location, into a newly-renovated area. The Director of the Política, the Secretary of the City Health Department, and other notables were present at a ceremony held in the morning, which also served as a venue for a silent protest by representatives of HIV/AIDS civil society, who donned clown noses to express just how short they felt the city’s response to the epidemic fell (fieldnotes, 1 December 2009).

The protesters were not the only ones who were not unequivocally pleased by the new furniture and gleaming-white walls. Apparently only a few of the clinic’s staff had approved the design of the new physical space; some of those who were not consulted felt the new layout made their jobs much more difficult to accomplish. Also, due to unforeseen electrical problems, it was very difficult to control the temperature in the new installations. The first few months of operations, coinciding with Porto Alegre’s summer, were uncomfortably hot ones for staff and patients alike. More grievously, the new location (upstairs in a building with no elevator service) was seen as a terrible obstacle to access for some patients, specifically those experiencing
mobility impairment as a result of HTLV-related neuropathy. One of the staff commented, “What are they supposed to do—crawl up the stairs?” Most of the patients I spoke with during observations in 2010 were ambivalent. They liked the clean, new feel of the space, but I frequently heard that the move had negatively impacted the ability to maintain confidentiality around their serostatus (fieldnotes, January-March 2010). In order to understand this perception, and its importance, some background information is necessary.

Individuals in this study, as in Brazil more generally (Rebhun 2004; Cataldo 2008; Miranda et al. 2013), believe that HIV-related stigma remains strong. Most of them manage their serostatus through selective (or a total lack of) disclosure. It is also important to know that, unlike the general population, which is assigned to receive health care in a particular location based on their place of residence, HIV-positive patients can choose where to be treated. For instance, patients from outside Porto Alegre can be seen at the municipal clinics if they are willing to make the trip. Over the course of my fieldwork, I spoke to at least a dozen patients (including the seropositive member of one of the participating serodiscordant couples) who made such a choice. Some of them explained that they had been diagnosed before specialized services were available where they lived and did not want to switch physicians, but others said they wanted to avoid being seen by people they knew (and, hence, identified as HIV-positive).
Regardless of a patient’s place of residence, prior to the clinic’s move, it offered a lack of visibility that patients found comforting. This was facilitated in two different ways. First, the previous location within the building made it unlikely that many people who did not have business with either the clinic itself or the harm reduction program would even traffic the hall leading to those areas. As such, the clinic was “hidden” (or ghettoized, depending on one’s view). Second, even the people who did pass by did not often see those inside, despite the fact the door to the clinic was always open. As Renato, an HIV-positive member a serodiscordant couple in this study, explained, even though he was employed at the Postão, he didn’t generally worry about his co-workers seeing him at the clinic. ‘‘When you’re sitting there…people go by—people that know me go by and they didn’t see me!...Because they pass by like this (puts head down), not looking to either side…. [as though to say,] ‘‘That world doesn’t exist for me. I don’t have [HIV], those are…dead people!’’

While the general public’s attitudes about HIV likely were not impacted by the clinic’s move, both the physical configuration of the new installations, and their location within the building entailed greater visibility for patients. Although it remained difficult to know—upon entering the building—where the clinic was located (to my knowledge, there was no directory), once one reached it, there could be no doubt about the population being attended, as a plaque and highly visible signage were posted outside. In and of itself, this might not have provoked complaints from the patients, but, whereas they had previously been allowed to wait inside the clinic, no matter how much in advance of their appointment they arrived, beginning in 2010, they usually had to wait outside the main clinic door after checking in. Patients were called to the inside waiting area only shortly before their scheduled appointment time. This, together with the patients, primarily because they disagreed with the amount and severity of stigma patients would face in other treatment contexts, even from health professionals.
much more heavily trafficked location of the clinic within the Postão, meant they were exposed to the informed (and, patients feared, judgmental) gaze of many more passers-by, for a much longer period of time than was previously the case. Whether and how this issue would be addressed remained an open question at the conclusion of the fieldwork period, but patients were not shy about sharing (with me) their concerns (fieldnotes, January-March 2010).

**Exposure to Biomedical Discourse on HIV: Treatment Flow**

Because it constitutes the primary mechanism through which clinic patients were exposed to biomedical discourse on HIV, including normative ideas about how to live with the virus, here I describe a typical trajectory through the clinic, prior to its re-location in December of 2009. While personal and clinical conditions can, of course, contravene this flow—particularly for those recently-diagnosed—most of the 6,000 active cases at the clinic were well-established patients and this description is intended to be representative of their experience.

After receiving a positive test result (often at COAS, which is down the hall and around the corner), patients are referred for treatment; initial appointments are usually scheduled over the telephone. When patients arrive at the clinic, they check in at a reception window, often staffed by college-level students completing internships. The patient’s paper file is pulled or created and walked across the narrow entry hall to the “triage area” while the patient waits in the adjacent waiting area. A nurse technician calls the patient into the triage room to take vital signs and weigh him or her. Male condoms, lubricating gel, and a logbook for documenting the distribution thereof are kept in the triage area, and I frequently observed the nurse techs ask patients if they wanted their allotment (15 condoms a month). Established patients most often did not wait for this question, but simply stated their need of these materials.

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26 This description is based on observations at the clinic in 2007 and 2009, informal conversations with patients, interviews with numerous staff members (especially one conducted on 24 August 2009), and extended discussions with the seropositive members of couples participating in this research.
The patient then returns to the waiting area, and the nurse tech places the patient’s file on a table there; separate piles are made for each physician working during the shift.\(^\text{27}\) From two to six physicians attend at a time; each appointment slot is 20 minutes long. Doctors (usually but not always infectious disease specialists) attend in an assigned examination room during the shift, coming out periodically to collect accumulated charts and call patients. Doctors usually arrive late, especially in the morning (there were a few notable exceptions, but it was common for the waiting area, by 9 or 10am, to be quite full with the backlog of waiting patients), and established patients are always aware of their particular doctor’s pattern of behavior in this regard.

After being called into the exam room, most patients sit in a chair facing a desk, which the doctors sit behind. Although each room has an exam table, based on my observations, physical exams are relatively rare, reserved for symptomatic patients (again, there are notable exceptions to this trend). At the initial appointment, and periodically thereafter, physicians order a series of tests (CD4 and viral load testing, screening for anemia, cholesterol, liver and kidney function, tuberculosis, etc.), most of which the patient can have done at the laboratory in the Postão. For follow-ups, patients have blood taken two weeks to a month prior to their scheduled appointment so that the results are available by the time they see the physician.

When patients’ clinical situations are under control, either because their CD4 count is still strong or because the drug regimen they take has proven effective, it is not uncommon for appointments to be over in ten minutes. In my experience, although physicians rarely missed an opportunity to reinforce the importance of adherence to ARVs, condom use came up somewhat

\(^\text{27}\) Morning shifts run from 8am to around 1pm; afternoon shifts run from 1-5pm. Doctors typically worked either in the morning or in the afternoon at the clinic, having a mix of other professional commitments (private practice, shifts at area hospitals, UBSs, supervising medical students, etc.) during the other half of the workday.
less often. This is at least partially because most doctors I observed did not systematically ask
patients about their sexual partners. When the issue did come up, their counsel amounted to
“Use a condom, every time.” For adherence issues, medication side effects, or minor health
problems, patients usually see a nurse first and their doctor only if necessary.

One type of appointment, however, takes longer and receives particular emphasis within
the clinic: the visit during which a patient is first prescribed ARVs. Although treatment
protocols in place during the period of this fieldwork were quite specific (accounting for clinical
situations beyond the interest of this chapter, for example), the general rule was for patients
begin ARV treatment when their CD4 count dropped to around 250. When this happens,
patients have an appointment with their physician, who completes the notification form for the
municipal surveillance unit, and they also see a nurse, for the first of a series of appointments in
what is called the ambulatório de adesão, or “adherence clinic.”

The procedure for the first adherence appointment includes completion (in interview
format, with the nurse asking questions and writing down the patient’s answers) of a
standardized form that remains in the patient’s clinic chart. It covers personal and contact
information, mode of transmission, as well as what is called situação de vida (“life situation”),
which includes things like living conditions; current partners; patient questions, concerns; and
any potential constraints to adherence. The nurse always stresses the importance of condom use
with all sexual partners, and explains the relationship of CD4 count and viral load. While some
patients already understand this, many do not—particularly those who begin taking ARVs
shortly after diagnosis. The particular combination of drugs the patient will take is also
described. Together the nurse and the patient settle on a dosing schedule that will facilitate the
patient’s consistent adherence to the treatment regimen. The results of these discussions, along
with any details the nurse thinks noteworthy, are recorded on the standardized form. The nurse then physically shows the patient which pills to take at what time; I also saw nurses draw pictures that patients took with them. The second and third appointments in this series are scheduled roughly 15 and 30 days afterwards, respectively, and are geared toward trouble-shooting and managing side effects of the ARVs.

This protocol is so important because it represents the most standardized and elaborated attempt by clinic staff to convey the biomedical narrative about HIV/AIDS to patients, and convince them to adopt and apply its prescriptions in their own lives. This is not to say that this information is not provided to patients at other times. On the contrary, one long-time staff member noted that a comparable procedure existed for each patient’s first appointment at the clinic. But staffing cuts led them to rely on nursing interns to carry this out; given turnover in this group and the academic calendar, it didn’t happen as consistently as they wished. Doctors also participate in the “education” effort. But the sheer volume of patients to be seen means that unless an initiative (“Explain viral load,” or “Ask patients about their sexual partners,” for example) is formalized, it may be only irregularly implemented. The ambulatório de adesão, in contrast, is a therapeutic ritual all clinic patients pass through when they begin taking ARVs.

Another stop in this very important round of appointments is a visit to one of the clinic social workers. While I was unable to observe these interactions, based on patient reports and an informal interview (4 September 2009) with a social work student completing her internship at the clinic, the goal of this appointment is to assist seropositive individuals in accessing what staff and patients alike call benefícios (“benefits”). In particular, the focus is on completing the paperwork required to be classified as fare-exempt for certain modes of public transportation within the city.
When I first visited the clinic in 2007, submitting this paperwork resulted in the issuance of the *carteirinha* (literally, “little card”), an identity card that served as general proof of one’s status as an AIDS patient. At that time, the *carteirinha* was shown to fare collectors on city buses to obtain fare exemption; this was intended to reduce structural barriers to accessing medical treatment. Alternatively (typically while the *carteirinha* was being processed), patients received small, plastic tokens called *vales* (“vouchers”) from the clinic. These same tokens were also provided to many formal sector workers as part of their compensation. *Vales* were highly desirable because, unlike the *carteirinha*, which stated that the bearer was fare-exempt for health reasons, they were “unmarked,” and therefore less stigmatizing. Also, if not needed, they could be sold for cash.

In 2008, however, an electronic fare-collection system was inaugurated within the city that incorporated AIDS-based fare exemptions. The system is based on a “smart” card, called the “TRI,” which can be swiped through electronic readers installed at the front of buses, allowing the bearer to pass through a turnstile and access the seating area. Various types of TRIs exist, including several for bus company employees and other transportation workers, one for formal sector workers more generally (whose cards are loaded with credit by their employers), one for students and teachers in the public school system (who enjoy reduced or free fares), one that any adult with a tax identity number can apply for and load with credit, and, finally, one for individuals that have been granted a fare exemption. This last category includes the elderly, disabled individuals (which can include those so-categorized for other, or temporary, health conditions), children receiving welfare, and “those sick with HIV who are in treatment” (Prefeitura de Porto Alegre N.d. Ônibus, accessed 13 January 2013). The TRI was described to me as an improvement over the previous system, since the card issued to AIDS patients is
visually indistinguishable from those used by other fare-exempt individuals. Thus, the TRIs used by participants in this study look just like the TRIs used by senior citizens and people with other qualifying health conditions, ostensibly precluding discrimination based on HIV status.

**HIV/AIDS-dependent Rights and Benefits in Porto Alegre**

The TRI is the only specifically municipal HIV-related *benefício*. Other benefits are guaranteed by the Federal government, or offered through NGOs (and, hence, not “guaranteed”). As a final consideration of the “setting” in which this research took place, I list and describe the legal rights of seropositive individuals, all of which derive from a “Declaration of the Fundamental Rights of Those Carrying the AIDS Virus.” This Declaration was approved at a national meeting of AIDS-related NGOs that took place in Porto Alegre in 1989. Based on the right of all Brazilians to “human dignity and access to the public health service,” it enumerates eleven rights, primarily guaranteeing access to information and treatment, confidentiality surrounding serostatus, and non-discrimination in all aspects of social life, including citizenship, work, and mobility (DDST/Aids/HV N.d.a).

The 1996 law establishing the specific right of Brazilian seropositive people to receive ARVs through the public health system has already been mentioned in this chapter. It bears noting here, however, that health programming at the Federal level continues to account for advances in scientific knowledge about HIV. For example, although it is not a “right” established by law, the aim of reducing MTCT is pursued throughout the country via *Programa Nascer*. This program, though administered at the municipal level, was established and is paid for by the Ministry of Health. It provides rapid HIV-testing (to be administered to parturients during labor), AZT in both injectable and oral solution forms, lactation inhibitors, and infant formula for mothers and newborns (CGAPSES 2012).
In addition to the right to treatment, the National Department of STDs/AIDS and Viral Hepatitis lists the legal rights of HIV-seropositive people in several domains; the juridical, financial, and laboral, while noting that concessions involving public transportation are state and municipal questions. Judicial rights are limited to free advising about HIV/AIDS-related issues; no automatic priority is given to court cases brought by seropositive people (DDST/Aids/HV N.d.b).

In the realm of finance, seropositive people have the right to exemption from paying income tax, and the right to receive the disbursement of their Fundo de Garantia por Tempo de Servico, or FGTS, account (DDST/Aids/HV N.d.c). FGTS is a type of obligatory savings account for those in the formal labor market. A percentage of workers’ earnings are deducted from their paychecks, and their employers also make mandatory contributions, creating a fund that can be withdrawn by the employee under specific circumstances. Qualifying events include leaving the company, being fired without cause, the purchase of a home, having one’s residence damaged by flood, or diagnosis with a number of serious health problems, HIV among them (CAIXA 2009).

Labor rights are the most extensive category, but simultaneously the least AIDS-specific. This is because the list includes rights that all formal sector workers have; what requires explanation is the specific circumstance(s) under which HIV/AIDS constitutes a justifiable basis for claiming them. HIV/AIDS-specific considerations include the right to maintain confidentiality of serostatus at work (HIV tests for placement or retention in paid employment are illegal). What might be called AIDS-mediated rights include the required qualifications for various categories of financial assistance, based on partial or total disability. Beneficio de Prestação Continuada, which is a type of monthly pension for those physically unable to support
themselves and who lack assistance from their families, is the only one of these that does not require previous contributions to Brazil’s social security system (made through formal employment). Workers with previous contributions can apply for either temporary or permanent disability status as a result of complications from AIDS. *Auxílio-doença*, or “temporary disability,” is the most commonly invoked status, and can be awarded for varying time periods, up to six months, at which point recipients must re-apply. *Aposentadoria por invalidez* indicates a more definitive disability; although termed “retirement,” it now requires renewal every two years (this was not previously the case; the laws regulating these benefits were revised in 2010). The application process for these benefits always requires medical documentation, and may require attendance at hearings before a judge (DDST/Aids/HV N.d.d).

**Conclusion**

This chapter has attempted to convey a sense of the socio-cultural, epidemiological, and historical context in which this research was carried out. As with any account that strives for a holistic rendering of social reality—at multiple scales—this one can be judged more or less convincing, adequate or inadequate, but never complete. Happenings which captured newspaper headlines for weeks have been entirely omitted (for example, seemingly interminable, separate political scandals that rocked both the state of RS and the Republic of Brazil during 2009), as have events that were likely of much keener interest to most of the participants in this study (e.g., the participation of a *Gaúcha* in the incredibly popular reality TV show, Big Brother Brasil). The information that has been included is simultaneously a frame for understanding why this particular research project was conducted, and a backdrop that should prove helpful in interpreting the findings.
In that sense, several main points deserve reiteration. First, the indispensable background to this study is the overwhelming importance of “difference” as an organizing logic of Gaúchos’ relationship with the larger Brazilian collectivity. This conviction of uniqueness is not entirely empirically unjustified, which suggests that, in accordance with Brazil’s famous regionalism (Skidmore 1999), it truly is necessary to confirm, rather than presume, the generalizability of national trends. Second, as befits a study relating to HIV/AIDS, local epidemiological data are presented and compared to national indicators, and the municipal policy response is examined. The proportional severity of AIDS in RS is clear, which is perplexing in light of all that—especially PT—administrations have done in response to the epidemic. Third, at both city and national levels, this chapter has illustrated important links between HIV/AIDS policy and historical forces and values (particularly health as a human right, as manifested through SUS). Fourth, of the principles that structure Brazil’s public health system, it is argued that universalism and decentralization—and, more specifically, municipalization—have potentially the greatest impact on the way individual Porto Alegremes experience HIV/AIDS treatment. Fifth, by considering the typical patient flow at one clinic, the effectiveness of biomedical management of AIDS becomes evident; it is fairly routinized, although not without challenges, which frequently stem from the pauperization of the epidemic itself. Finally, in spite of scientific advances in treatment options, and laudable public health and legal measures, AIDS-related stigma remains a primary concern of clinic patients.
CHAPTER 3: LITERATURE REVIEW

Introduction

In order to productively address the research questions posed by this dissertation, a review of relevant literature is necessary. This review centers on risk as it relates to HIV, as this was the conceptual and theoretical foundation for the fieldwork undertaken in Porto Alegre, but also includes a specific section on HIV serodiscordance. After all, in order to understand how HIV-serodiscordant couples construct risk, we must ask what risk is, as well as review what is known about serodiscordant couples. The more focused literature pertaining to this dissertation’s secondary research question, regarding practices of citizenship based on HIV serostatus, is only briefly touched upon. Instead, it is explored in Chapter 7, together with the presentation of those data. Overall, the discussion offered here prioritizes anthropological treatments, with public health approaches constituting a necessary complement. Throughout the review, I have chosen to focus my consideration by geography and mode of transmission, in addition to academic discipline. Where possible, therefore, I attend to scholarly work conducted in Brazil, preferably with heterosexual couples, though no a priori exclusions were made. In reference to certain topics I rely heavily on research in other contexts, as analogous Brazilian studies are simply lacking.

A word as to the organization of the essay: because early research on the epidemic did not tend to problematize the concept of “risk,” a brief and selective history of anthropological work on HIV/AIDS serves as the starting point for discussion. Conceptualizations of risk therein are noted, although that frequently is not the primary discussion engaged in by the authors. In a
second section, I then examine models of risk typically employed in public health, especially epidemiology. This framing is more than merely expository, as critiques of public health approaches to risk and disease prevention—often lodged by medical anthropologists—heavily informed my thinking on this topic. As such, they are part of the genealogy of my work, and my presentation of them is intended as a transparent indication of disciplinary positionality.

In the third and fourth sections of this chapter, I offer a view, firmly situated in anthropology, of a dialectical process of refinement and innovation of the meaning of “risk.” Specifically, I examine how conceptualizations of risk in anthropology might be understood through the application of a broad idealist-materialist rubric. In the fifth section, I examine literature on HIV-serodiscordant couples, with an emphasis on qualitative research, heterosexual couples, and recent publications. The goal of this chapter is to make explicit the theoretical roots that informed my research, and provide context for interpreting the data I collected. Therefore, in the conclusion, I summarize the most important findings to carry forward from the literature reviewed here, as they structure the analysis presented in subsequent chapters of this dissertation.

**A Short History: Anthropology of HIV/AIDS in the 1990s**

Although anthropological treatments of HIV/AIDS, its prevention, and even risk, are now numerous, the discipline did not immediately engage *en masse* with the epidemic. The important early work done on the issue in other fields was often oriented by a paradigm that Waterston (1997:1381) termed “biomedical individualism.” This, in many instances, grew out of and was guided by “one of the most widely used theoretical models in public health” (Coreil, et al. 2001:79; Bloor 1995): the Health Belief Model. This model is based on an individual’s 1) perception of her or himself as being “at risk,” 2) estimation of the severity of the condition for
which s/he is at risk, and 3) judgments of how effective any recommended prevention/remedial efforts are likely to be, compared to the “cost,” broadly construed, of implementing them.

The emphasis on individual knowledge and perception led medical doctors, psychologists, and public health professionals who were confronting the anguish and terror caused by the new disease to zero in on two priorities: 1) the dissemination of information about HIV/AIDS risk; and 2) behavior modification on the part of individuals (Parker 2001:164). It is not difficult to understand why. It must have seemed beyond reason to professionals who dealt with AIDS-related deaths on a daily basis that susceptible individuals, confronted with what was, at the time, an inevitably fatal disease, would not change their behavior once educated about their risk. Social scientists were drafted to the cause, but by the late 1980s, many had concluded that the Health Belief Model was simply inadequate to deal with HIV/AIDS. As Bloor (1995:20) notes, theories “which conceptualize risk behavior as a volitional and individual act are inappropriate where risk behavior involves two parties… and where practice may be characterized by constraint, rather than by free choice.” Thus, much of anthropology’s production on this topic focused on problematizing the assumptions of the dominant model, and documenting how it worked—or failed to—in particular contexts.

Richard Parker and Brooke Schoepf concur that anthropological research on HIV/AIDS during the 1990s was quite different than in the preceding decade. Major contributions include problematizing epidemiologically-derived “risk groups,” and questioning the application of those categories to the epidemic in other contexts. Singer (1998:13) provides an example drawn from his own work that demonstrates not only a typical line of anthropological argument, but also an awareness of the damage caused by dominant approaches to risk:

The exposure categories that guide contemporary AIDS prevention often are not culturally meaningful to targeted populations. Being in a sexual relationship with an [injection drug user.] IDU, for example, does not
create a common identity nor does it produce shared behavioral traits. Some such people are wives or husbands, others are lovers, others are passing acquaintances or customers. However, creation of the epidemiological category ‘sexual partner of an IDU’ allows the perception to continue that only certain people, people who are marginal to mainstream society, are at risk for AIDS. At the same time, it provides a rationale for treating people with AIDS as dangers to rather than part of society.

Glick-Schiller, Crystal and Lewellen (1994:1341) extend this argument by noting that reifying particular practices into something often called “culture,” which was seen as immutable and equated with particular “risk groups,” served handily to “objectify and distance.” Schoepf went even further, arguing that biomedical models’ motivational subtext was to “maintain, reinforce, reconstruct, and obscure the workings of the established social order” (Schoepf 2001:338). Although de rigueur today, asserting that the concept of “risk groups” served mainly to obfuscate differences among “group” members and give individuals not belonging to such groups a psychological carte blanche to continue their own risky behaviors posed a serious challenge to prevalent thinking during the early epidemic. This led to two major trends in anthropological work on HIV/AIDS during the rest of the decade. The first was a focus on context-specific examination of cultural practices and the meanings of disease. The second involved a recognition that wider structural factors, on regional, national, and global scales, influenced individuals’ vulnerability to infection and constrained their ability to take preventive measures (Parker 2001:165; Schoepf 2001:335).

The first approach has been characterized as a shift away from an etic perspective in considering HIV/AIDS risk (Parker 2001:167). It produced a deepened appreciation of why U.S.-derived epidemiological categories were often inappropriate in other contexts—and occasionally even when used domestically. Important work illuminated the cultural construction of sexuality and commercial sex work, focusing on the varying propensity of concepts to
encompass wide ranges of behavior (e.g., Parker and Tawil 1991; Gil 1991; Bloor et al. 1993; Romero-Daza 1994; Singer and Marxuach-Rodriquez 1996; Parker 1996; Whitehead 1997; Klein 1999; Carrier and Magaña 1991). These highly-contextualized examinations of HIV risk incorporate such basic anthropological considerations as “with whom one may have sex, in what ways, under what circumstances, and with what specific outcomes” (Parker 2001:169). Also influential was research carried out on local understandings of disease, including those of traditional healers and the general population (e.g., Ingstad 1990; Romero-Daza 1994; Knauth 1998, 1997a, 1997b; Knauth, Víctora, and Leal 1998; Willms et al. 2001; Marmo da Silva and Chagas Guimarães 2000). This research elucidated important ways that the sociocultural environment entailed differential exposure to, or constraints in dealing with, HIV/AIDS risk that, previously, had frequently been overlooked. It bears noting, however, that on the most fundamental level, this work generally concurs with certain biomedical assumptions about risk. That is, it assumes that—if conditions permitted—people would avoid exposure to HIV; risk is seen as inherently negative.

Gender as a contextual factor in HIV risk may have provided a bridge from the focus on cultural specificity to larger, structural forces, because gender inequality is both a “local” and global phenomenon. Rather than examining the effect of gender as a binary system, however, much of this work focused on the cultural norm of female subordination. As a component of HIV risk, it was found significant (as, indeed, it is to this day), and to have political economic implications as well, whether it had been codified into law (Romero-Daza 1994) or was merely a de facto reality (Goldstein 1994, 1992; Scheper-Hughes 1994, 1992; Waterston 1997; Schoepf 2001). It should be mentioned that this work revealed that “women,” just like any other group, are not uniformly “at risk” (an observation also made by Schatz 2005, upon consideration of
similar work). Marital status, socioeconomic class, age, religion, ethnic group, education, parity, and nationality were portrayed as impacting women’s ability and desire to recognize and minimize HIV risk. In addition, the role(s) they occupy at a given moment, for example, as commercial sex worker (CSW) or girlfriend (Schoepf 2001:344; Romero-Daza, Weeks, and Singer 1999; Waddell 1996:77; Sibthorpe 1992), make a difference. What was given less attention at the time was the way such characteristics and structural positioning also impacted men’s vulnerability, albeit in different ways. An analysis of the role of masculinity in HIV risk still lay in the future (but see Knauth 1998), but the assumption that social actors could or would make “free” and consistent decisions to avoid infection was steadily called into question.

More generally, in a political economy of health approach, gender-based oppression joined factors of poverty and racism as key components in models of HIV risk (Parker 2001:168,170; Schoepf 2001:343-345). Anthropologists also specifically considered, for example, social exclusion, unemployment, and migration as contributors to HIV risk via heterosexual transmission (e.g., Sobo 1995; Waterston 1997; Romero-Daza 1994). Two of the most well-known proponents of this “structural violence”/social inequalities approach were (and are) scholar-activists Paul Farmer (2001, 1996, 1992) and Merrill Singer (1998, 1994; Singer and Snipes, 1992; Singer and Marxuach Rodriquez 1996). Their work, aside from being widely cited, also pushed the boundaries on conceptions of risk. Singer and Snipes (1992:225; see also Singer 1994:933) noted that:

The contemporary health crisis of the North American inner-city…is characterized by a set of closely interrelated and mutually reinforcing endemic, epidemic, and pandemic conditions. Consequently, we have urged the use of the term *syndemic* to call attention to the synergistic nature of the health and social problems facing the poor and underserved.

AIDS, in their view, was just one of these multiple problems, thus undermining what many scholars (e.g., Crane et al. 2002; Squire 2010) have called “AIDS exceptionalism” (at its
broadest, this is the idea that HIV/AIDS is somehow different than other health issues, more pressingly, special). Singer also turned another bit of conventional wisdom on its head when he argued (1994:937) that “In [the context of an overall inner city health crisis], AIDS itself emerges as an opportunistic disease, a disease of compromised health and social conditions, a disease of poverty.” In a similar vein, Farmer (2003:7) is known for saying “risk for HIV goes hand in hand with not having. The have-nots constitute the global risk group, if there is such a thing.”

Such statements, in isolation, might seem akin to what came to be known as the “dissident” position on the etiology of AIDS that emerged, and was forcefully excoriated, in South Africa. Compare the foregoing excerpts to segments of Thabo Mbeki’s infamous 9 July 2000 speech: “The world’s biggest killer and greatest cause of ill health and suffering across the globe is listed almost at the end of the International Classification of Diseases. It is…extreme poverty…As I listened and heard the whole story told [about AIDS in South Africa], it seemed to me that we could not blame everything on a single virus” (cited in Fassin 2007:15).

Of course, the two positions—that taken by Singer and Farmer, and that taken by some of the “dissident scientists” on Mbeki’s Presidential Panel—are not the same, since the latter actually did question whether a necessary relationship existed between HIV and AIDS, while the former did not. Farmer, as a physician, fought (and fights) strenuously to extend ARV coverage to the world’s poor; Singer (1998:18) lists epidemiological and “biological factors (e.g., viral strain, preinfection health of the population, efficiency of various transmission modes)” along with cultural practices, social factors, and “political economic facts” as important causes of the epidemic. The point here is not to play with artfully truncated quotations, but simply to make visible how, at this point in the epidemic, problematizing HIV “risk” was a delicate matter. Rather like Nixon going to China, one needed the right allies and background in order for such
an intellectual move to even be possible—and that background seemed to preclude a wholesale reconsideration of the meaning of risk; no one suggested that risk for HIV could be seen in a positive light.

In the midst of all the critical attention the epidemic was receiving from anthropologists, what might explain this lacuna? We can perhaps generalize Singer’s (1998:22) cogent observation, regarding the goals of research situated in the political economy of health perspective, to the discipline as a whole:

The objective … has not merely been to understand the spread of AIDS and people’s responses to it, rather, the full agenda of this approach includes a driving concern with the development of useful knowledge and a commitment to collaboration with people living with AIDS and at high vulnerability to AIDS in the development of effective and sensitive programs of prevention, support, and advocacy.

In order to appreciate the impetus behind this research, one must remember that combination therapy including protease inhibitors—a true revolution in HIV treatment—was not discovered until 1996. Which is to say, more than half of the decade considered in this section had passed before there was reason to believe HIV/AIDS was on its way to becoming a chronic disease. The environment was still one of crisis. And as in any crisis—health-related or otherwise—our urgent need to respond, or what Didier Fassin calls a “sense of the tragic,” may lead to “cutting short the observation and interview time necessary to comprehension” (2007:xiv). Knowledge cannot be divorced from the context of its production. While HIV risk was associated with imminent mortality, asking certain theoretical questions must have seemed an indefensible, luxury.

As the epidemic grew, the need for deeply contextualized studies, as well as work that traced the linkages between individual infection and the global political-economic order that structured it, became—if anything—more pressing. Accordingly, after the turn of the new
millennium, anthropologists continued to produce analyses of HIV/AIDS (and, most importantly, the people affected) that can be traced to these two basic types of research. However, innovations in the biomedical management of HIV opened new possibilities for living with the virus, which also engendered new anthropological questions about that lived experience. Thus, accounting for changing conditions, and building on previous scholarship, the anthropology of HIV/AIDS has “complexified” since 2000, attending critically to more issues and often seeking to bridge previous divides. It strives to document, as Fassin has written, “history at work at the global level and history as lived in local space; the state politics and the politics of subjects” (2007:xvii). Before turning to this production, however, this review pauses to consider some of the typical approaches to HIV risk from public health, especially epidemiology.

Public Health Approaches to HIV Risk

As previously mentioned, approaches to HIV risk from medicine and public health (especially epidemiology) largely set the tone of early research on AIDS. If it is perplexing that a discipline concerned with populational health should have so institutionalized individual-level factors as the key to HIV prevention, again, the context of the 1980s is instructive. In the panic surrounding the new affliction, in the absence of an identified causative agent or mode of infection, all that could be done was to collect, and then aggregate, individual-level data. Even in the early 1990s, as knowledge accumulated and trends over time became discernible, public health practitioners were facing the same imperatives mentioned in relation to anthropological studies: to put expertise to work, intervene, save lives. It should not be discounted that, for those who can and wish to, modifying behaviors has been an effective way to reduce risk for HIV. Interventions produced by the sub-disciplines of public health have helped people to do just that,
sometimes even producing other tangential benefits in the process (e.g., Kalichman 2005; see also Fisher and Fisher 1992; Pequegnat and Bray 2012).

Nevertheless, partially due to their preeminence, risk models derived from “the Theory of Reasoned Action, the Health Belief Model, Self-Efficacy Theory, and the Stages of Change Model” (Singer 1998:14) have been thoroughly critiqued. Some of the more common criticisms include the unwarranted divorce of an individual from his or her sociocultural, historical, and economic context; the essentialization of practices into “identity;” and the presumption that disease prevention always takes priority in people’s decision-making processes. Public health scientists have taken such objections seriously and assimilated them in their research and interventions; this uptake, however, is uneven. It is still possible to find new publications (particularly from epidemiologists) that treat sexual orientation, or race/ethnicity, or gender, for example, as labels for some sort of naturally occurring risk in relation to HIV, rather than as effects of particular culturally-, and historically-specific forms of social organization (see below).

On the other hand, even scholars that take issue with such framings rely on the statistics thereby produced. For example, without data on the vastly disproportionate number of HIV and AIDS cases among the African American community in the U.S. (Friedman, Cooper, and Osborne 2009:1004; Brooks et al. 2012:1518), how would medical anthropologists (and others) support their arguments for the risks posed by racism? Likewise, to give just one more example, without documentation of the increasing proportion of incident AIDS cases among women in Brazil, there would be no grounds for claiming the feminization of the epidemic (Polejjack and Costa 2002). Particularly for applied anthropologists, who do their work with an eye to solving human problems, this is a necessary and complementary relationship. Anthropology as a
discipline need not, and should not, occupy itself with collecting and monitoring surveillance data, for example—just as public health researchers (and, more specifically, epidemiologists) need not bear the responsibility for collecting contextualized stories of health and illness, and connecting them to the nature and meaning of the human experience. Each discipline can, however, constitute a public to which the other is accountable and from which to learn. The following section is offered in precisely this spirit.

Osborn’s (1988) treatment of the AIDS epidemic in Annual Review of Public Health was chosen as a point of entrée. Much of the review was given over to immunology, serology, cellular pathology, etc., which were assumed to follow universal processes. While the urgent need to disseminate this basic information should not be discounted, one can still note (with the benefit of hindsight) that the tight focus on the virus and its natural history seemed to obviate any consideration of humans as diverse, socially-situated beings. The impact variation might have, even in the biological capacity of hosts, is simply not entertained. For instance, there is a reference to the “mystery” of the infection’s ability to diffuse quickly through networks of IDUs sharing equipment, when “needlestick injuries and splash exposures of health care personnel have been virtually risk free” (Osborn 1988:559). Such statements clearly leave no room for the possibility of differing value systems and constructions of risk, which, again—given the timeframe—perhaps should not be surprising. It is fair, however, to call attention to the omission of even basic analytic considerations like the difference in frequency of exposure—needlesticks being exceptions in healthcare settings, while needle sharing is comparatively

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28 This choice was not simply arbitrary, but justified by three considerations: 1) The piece was published around the same time as the earliest articles considered in the “Brief History” section above, 2) it was published in an important journal in the field of public health, and 3) Osborn’s review was one of the last to take on the epidemic as a whole.
common in (some) IDU networks—as well as the probable difference in overall states of health between health care professionals and IDUs.

Also, there is a clear tendency for risk group thinking and essentializing to guide Osborn’s discussion. The most efficient means of sexual spread of HIV is said to be “anal receptive, homosexual intercourse” (Osborn 1988:560). In reviewing the evidence for the relatively inefficient, but possible transmission of HIV infection from women to men, the discussion revolves around the ability of commercial sex workers (“prostitutes”) in Africa to infect their male clients (Osborn 1988:560). The only real mention of a sociocultural variable is “race,” but it is used as a proxy for illicit behavior, since Black and Hispanic patients are said to be “more likely to be IDUs or to be sexually involved with IDUs” (Osborn 1988:570). And under the heading “Treatment and Care of Different Populations,” the author notes that the switch from a predominantly homosexual patient base to an IDU base, “presented much more frustrating treatment problems” that have “intensified the profoundly discouraging impact on health professionals” (Osborn 1988:567, my emphasis). The implicit conclusion is that only certain kinds of individuals are at risk for HIV: “homosexuals” (apparently the only people who have anal intercourse), “African heterosexuals” (who are portrayed as hypersexualized and promiscuous), and minority patients (who must be drug users). There is the faintest attendant suggestion that those individuals should regret the toll their illness exacts on their doctors.

This is not merely a function of one review taking on too much analytical ground, or of one author’s flawed perception. Had the epidemic not been initially and prominently conceptualized in terms of stigmatized risk groups, such constructions would not have surfaced.

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29 Although to reiterate, and be fair: later HIV-related reviews fragmented into topics: effectiveness of HIV prevention in the U.S., economic evaluation of HIV prevention, HIV/AIDS in children, HIV/AIDS in the 1990s, and International Aspects, among others.
in Osborn’s work. Today, it is obvious why such renderings are offensive and counterproductive, but this is in retrospect. In any case, the most notable aspect of her article is not its ethnocentric moralism. It is, rather, the lack of what I would argue defines the mainstream public health approach to risk today: quantification.

Virtually every article included in this review features at least one table of quantitative results, displaying statistical associations between dependent and independent variables. The most authoritative treatments employ parametric statistical tests (often linear or logistic regression) on data from relatively large sample populations and report 95% confidence intervals (Brennan et al. 2012; Galletly et al. 2012; Kurtz et al. 2012; Speizer et al. 2011; Powers et al. 2008; Kreitchmann et al. 2004; Hearst et al. 1999; Guimarães et al. 2008; Israel et al. 2005; Witte et al. 2007; Padian et al. 1997; Pechansky et al. 2004; van der Straten et al. 1998b). Even some fundamentally theoretical articles, as well as reviews and qualitative studies with small sample sizes (Lanier and Sutton 2013; Linley et al. 2012; Brooks et al. 2012; Hoffman et al. 2012; Marqués et al. 2007; van der Straten et al. 1998c; Bunnell et al. 2005; Bajos and Marquet 2000) offer tabulations of survey results or descriptive statistics pertaining to the study population.

This emphasis on the quantification of risk is, according to Ayres et al. (2006:384), the latest stage in the historical development of the discipline of epidemiology, which stretches back hundreds of years. Lupton (1999:6) agrees, noting that during the 1700s the discipline already “had begun to be scientized, drawing upon new ideas in mathematics relating to probability.” The concept of “risk,” in fact, was distinguished from the notion of “uncertainty” precisely because, to qualify as risk, “the probability estimates of an event are able to be known” (Lupton 1999:7). Though Lupton (1999:8) suggests that this distinction has largely faded for society as a
whole, Ayres et al. (2006:386) demonstrate that truth claims in epidemiology are “more and more circumscribed to the construction and verification of the formal (mathematical) necessity of probabilistic associations.” Overall, this assertion is borne out by the work considered here. Even in a review of publications on “risk perception and communication,” for instance (in which one might anticipate slightly more flexibility with regard to defining risk), lay perceptions of risk were compared to, and found to be incorrect to the extent they diverged from, quantitative measures derived from epidemiological studies (Fischhoff et al. 1993:194).

Numerous studies boast impressive sample sizes, employ appropriate—even innovative—quantitative methods, and produce informative results about risk. The 1997 report on the landmark ten-year study of heterosexual transmission of HIV in Northern California (the Partners Study) is a good example. The recruitment criteria were stringent, and every reasonable effort was made to control confounding factors (especially IDU) and other types of bias in participant selection, data collection, and analysis. Important findings included an estimate of constant per-contact infectivity of HIV for male-to-female transmission of 0.0009, with female-to-male infectivity being approximately seven to nine times less efficient (Padian et al. 1997:354). Also, over time couples were less likely to report consistent condom use and, in a logistic regression analysis, the factor with the strongest effect on seroconversion (adjusted odds ratio = 2.6) was history of a sexually transmitted infection (STI) (Padian et al. 1997:353-354).

In much the same way, although with a smaller sample and an exclusively cross-sectional design, Pechansky et al. (2004) report that being older than 30, having fewer years of formal schooling, being low-income, and having injected drugs are factors associated with HIV seropositivity among drug users in Porto Alegre, Brazil. Likewise, after a couple-based HIV/STI intervention, Witte et al. (2007) report multiple characteristics, (e.g., a relationship of at least six
years’ duration, low relationship satisfaction, and Latino ethnicity or HIV-positive status of the male partner) that are associated with discordant reports of various risk behaviors in U.S. couples. And Israel et al. (2005:7) find that seronegative members of HIV discordant couples with high scores on a scale of “sexual sensation seeking” were between four and five times more likely than respondents with lower scores to report unprotected sex (vaginal, anal and/or oral).

The quarrel, if there is one to be had with these studies, is not over the findings per se, but what those findings mean, that is, what they tell us about risk in the multiple and contingent contexts where HIV transmission actually and potentially occurs. In the Partners study, the results seem to indicate that HIV prevention could be usefully undertaken in STI clinics, but they don’t tell us much else—mostly because variables that were then proving relevant to the epidemic, like minority ethnic group membership and socioeconomic class, were excluded from the analysis. The Pechansky et al. study claims as its goal quantifying "a known clinical reality" (2004:1659) about transmission among drug users, but the study never asks why those particular characteristics, as opposed to others, lead to a greater likelihood of transmission. The only attempt at explaining their findings is a statement to the effect that having more years of formal schooling is protective because those who were in school longer are "more capable of receiving and using information" (Pechansky et al. 2004:1658). No support or justification is offered for this assertion, and, clearly, many alternative hypotheses could be generated. The Witte et al. (2007) study does very little in the way of synthesizing the multiple findings reported; it seems more an exercise in identifying statistical significance than a monograph guided by any theory of the biosocial phenomenon being studied. Finally, Israel et al. (2007:9) investigate a predisposition to sensation seeking as a possible explanation for the frequent disconnect between knowledge and preventive behaviors in sexual interactions, but the “sensation” ostensibly being
sought is unclear, and—more importantly—there is no discussion of what is gained from such a predisposition. That an association was found between sensation seeking and unprotected sex therefore means little (of note is that they designate significance at alpha = 0.10, a more permissive standard than that used in the rest of the quantitative research reviewed here) (Israel et al. 2007:8). The exclusively quantitative findings of other studies (van der Straten et al. 1998a; Hearst et al. 1999; Stein et al. 2006; Guimarães et al. 2008; and, to a limited extent, Kempf et al. 2008) raised similar questions.

This, again, is not to say that such studies do not generate important knowledge. I agree with Ayres et al. (2003:123-124) that “Establishing probabilistic associations of the populational distribution of infection among different objective, measurable conditions such as sex, age, profession, sexual practices, etc. will continue to be an important source of information and hypotheses.” My argument is simply that by itself this knowledge is incomplete; risk is much more complicated than these numbers suggest. Too much is left out when we only acknowledge the reality that fits within quantitative, biomedically-derived models.

The poverty of dismissing certain (non-scientific, non-quantitative) conceptions of risk is apparent in a study by Bunnell et al. (2005) on HIV-discordant couples in Uganda. These couples had presented at an established Voluntary Counseling and Testing site and enrolled in a serological study; at a follow-up visit they participated in in-depth interviews or focus groups designed to elicit their explanations of serodiscordance. According to the authors, few clients (or their counselors) reported “accurate” information about HIV serodiscordance. Instead, couples often believed that the seronegative member of the couple was either actually infected (but did not produce a positive test result), protected by God, could only be infected through “rough” sex,

30 None of the studies claiming to conduct “focus group research” met Krueger and Casey’s (2000) criteria for adequate data collection methods (i.e. sufficient numbers of groups, stratified by variables under consideration, etc.)
or was immune to HIV (Bunnell et al. 2005:1002-1005). These explanations are categorized as “false,” and are only given further consideration in so far as they are seen to reduce couples’ motivation to engage in safer sex practices.

Yet, some of these responses clearly are part of a different belief system—one that, if understood, might in itself facilitate HIV prevention—and others, namely the “immunity” idea, may eventually be borne out by new immunologic research. This is an unfortunate and archetypal example of the way much of the literature on serodiscordance uncritically accords priority to biomedical models of risk. As this trend is further explored below, we need only note here that the researchers’ assumptions have, in this case, blinded them to what may be the most telling data they collected. In the process, they’ve missed an opportunity to engage with human beliefs and experience in all their complexity—the very same complexity that structures the spread of the infection they are so interested in halting.

To generalize these criticisms to “public health scholarship” would, however, be unfair. These issues are less frequently present in studies guided by psychosocial paradigms or social epidemiology. In such treatments, risk can often be quantified, but the categories used in analysis are given more reflexive consideration. This is not necessarily a “lesson learned” over time; some of the earliest articles included here are cognizant of the politics of knowledge production and everyday life. In the same year, for instance, as Osborn published her review of HIV/AIDS, Mays and Cochran (1988) discussed HIV risk perception among Black and Latina women in the United States. Although their treatment of “poor people” tends slightly to essentialize the lives of minority women, the authors raise multiple important points. First, they remind their readers that marginalized women deal with many risks on a daily basis, of which HIV infection is only one. Second, they make explicit the relationship model on which HIV
prevention messages were based at the time, and question whether that model adequately describes the contexts in which Black and Latina women would implement such behaviors (Mays and Cochran 1988:954). This leads them to argue that “Current messages advocating knowledge of the sexual history of one’s partner and discussing ‘safer sex’ before sexual involvement ignore [normative, culturally-based] expectations for women’s behavior” (Mays and Cochran 1988:952). Finally, they urge those involved in prevention efforts to be cautious in making recommendations for women to become competent “condom negotiators” under such circumstances (advice that is heeded by van der Straten et al. (1998a) and Witte et al. (2007) only in the breach, although van der Straten et al. (1998c) echo the sentiment).

Psychology is not the only paradigm that allows one to be cognizant of the social context in which research is conducted, however. The studies by Kelly et al. (1994), Kreitchmann et al. (2004), and Maia et al. (2007) offer examples of a variety of approaches that still manage to take these factors into account. Although the importance of knowledge and self-efficacy in the intervention discussed by Kelly et al. (1994) clearly mark it as being anchored in social cognitive theory (Quinn and Coreil 2000:83-85), the authors place the study’s participants in a more holistic framework. They acknowledge that, as “inner-city women,” the study population has to confront—in addition to HIV risk—“many other concerns and problems related to social disadvantage” (Kelly et al. 1994:1918). Kreitchmann et al. (2004) report on a classically epidemiological study of perinatal HIV-1 transmission in Porto Alegre, Brazil, finding only maternal viral load at study enrollment to be significantly associated with maternal to child transmission (MTCT) (Kreitchmann et al. 2004:582). However, their use of a social ecological model (Coreil et al. 2000:10) leads them to interpret the quantitative “non-results” as being actually quite important: implementing Brazilian policy guidelines with respect to HIV-positive
pregnant women reduced the MTCT rate from 39.8% to 3.2%, “despite poor socio-economic conditions” (Kreitchmann et al. 2004:579).

A similar concern with context—this time sociocultural—animates the discussion of results obtained from a questionnaire administered to two groups of individuals in the Federal District of Brazil, all of whom were in either formal or common-law marriages. The aim of the study was to elucidate the “knowledge, preventive behavior, and perception regarding HIV/AIDS” (Maia et al. 2008) of partnered heterosexual individuals. In general, levels of HIV/AIDS-related knowledge were high. Significant differences did exist, however, between the two groups—most importantly, the poorer group with fewer years of formal schooling had less detailed knowledge of HIV. The authors attribute this to a lack of access stemming from the group’s social marginalization (not to a diminished ability to process information, as Pechansky et al. suggest). Also, rates of consistent condom use were low, around 14% for intracouple interactions. This is attributed to the meanings of both condoms and primary affective relationships within Brazilian culture (Maia et al. 2008:3, 5). These interpretations of survey data are based on particular conceptions of the nature of society, as documented by researchers who work at the nexus of public health and epidemiology in Brazil, and also accord well with the “official” epidemiological discourse in Brazil that sees social inequality as a risk factor, and, hence, relevant to the distribution of disease.

Some newer, U.S.-based studies also take official interpretations of epidemiological evidence as their starting point. The “graying” of the epidemic, for example, has been notable for some time (Radda et al. 2003), and two recent studies, both published in the American Journal of Public Health, examine aspects of this trend. Brooks and co-authors (2012) claim to

31 It should be noted, however, that these “national stories” are quite different; the U.S. version does not incorporate social inequality in anything like the same way the Brazilian one does (see http://aids.gov/federal-resources/national-hiv-aids-strategy/nhas.pdf).
provide “The Public Health Perspective” on HIV and older Americans; Linley et al. (2012) focus specifically on racial/ethnic disparities in HIV diagnoses from 2005-2008 in those older than age 50. There is consensus that a lack of personalization of risk from HIV, combined with continuing sexual activity (including male same-sex practices) and low rates of condom use, creates opportunity for infection among older adults. Linley et al. (2012:1527) also discuss drug-related risks, and Brooks et al. (2012:1516) identify gender-specific considerations, which include biological changes in the vaginal epithelium and cervix for women, and, for men, the availability of drugs to treat erectile dysfunction and greater availability of sex, including commercial sex and meeting partners via the Internet.

Although these studies overcome the cultural tendency to presume that older people have given up sexual activity, in other ways they do not provide evidence of critical consideration of HIV-related risk. In the presentation of gendered sexual risks mentioned above, for example, Brooks et al. (2012) biologize women’s relationship to sex and, hence, HIV; desire’s role is invisible. On the other hand, for men, sexual desire is portrayed as fundamental—motivating them to take Viagra and arrange hook-ups online. As no evidence is presented to justify this divergent treatment, we are left to conclude that it springs from anachronistic cultural preconceptions about men and women’s roles in negotiating sexual interaction: women are bodies to be penetrated by men who can’t be satiated.

In addition, the authors assume continuity in terms of predominant modes of transmission between older and younger populations, although they offer no data on this (which, to be fair, may be considered beyond the scope of the article). They urge clinicians to suggest HIV testing to older patients if it seems warranted after “a thorough assessment of risk including sexual activity, number and types of sexual partners (i.e., commercial sex worker, same-sex partner),
and other potential risk factors” (Brooks et al. 2012:1516). But which routes of exposure would be most relevant to consider for this group is a question that deserves more attention. Linley et al. (2012:1528) note that well over a third (42%) of HIV notifications to the CDC regarding people over age 50 did not include “an identified risk factor” (for those aged 13-49 years, that proportion was 32%). Their analysis, however (which included attributing unassigned cases to a mode of transmission through a statistical procedure called multiple imputation), highlighted some important differences between age groups. Among older men, more incident HIV cases were related to IDU and heterosexual contact (as opposed to MSM) than in younger people; for older women more cases related to IDU (as opposed to heterosexual contact). No explanation is advanced for this finding, and neither article thinks beyond established epidemiological categories to ask how HIV risk (and therefore modes of transmission) might be structured by age, and hence differ from ways it is experienced by younger people. For example, the potential for social isolation, and the gender imbalance that characterizes the elderly population in the U.S. never enter the discussion.

Neither is the demographic profile of incident cases among older people considered for the light it can shed on risk. Both Brooks et al. (2012:1518) and Linley et al. (2012:1529) note that the disproportionate representation of African Americans among those over age 50 who were diagnosed with HIV in 2005-2008 was even greater than for younger groups, but neither engage with this finding on a structural level. In fact, Linley et al. (2012:1530) appear to expend considerable effort to avoid bringing up, for example, the way differential access to medical care may contribute to the disparity:

A possible contributor to this increased disparity is the potentially longer transmission period for older persons who are tested later in the course of infection. Recent studies suggest that among African Americans compared with Whites, there is a greater prevalence of concurrent partnerships, more segregated partner choices, and more sexual bridging
between high-risk subgroups and the general population that contribute to increased HIV transmission and help sustain disparity in HIV rates. The higher likelihood of Whites to be diagnosed earlier, leaving a more disproportionate number of infected minority adults who do not learn of their infection until they are older, may also account for some of the increased disparity.

Because the “higher likelihood of Whites to be diagnosed earlier” is not explored critically, but is stated as a fact (the footnote the authors include after that phrase only references epidemiological data from the CDC), the passage allows for the conclusion that African Americans simply choose to be tested later. This in turn implies that it is the choices (essentially having more sexual partners from “high-risk” groups” and late testing) made by this heavily-affected group that are primarily responsible for their health status. While articles like these two should not be tasked with accounting for the extensive literature on social determinants of health (as that was clearly not the authors’ focus), a rhetorical nod to ways such considerations might be implicated in reported findings is not too much to ask.

Plenty of public health researchers do this and more. Lanier and Sutton (2013:262) observe that “despite constituting only 13% of the total US population, Blacks represent 52% of new diagnoses of HIV infection and the burden of disease rests most heavily on Black men, particularly MSM.” They attribute this disparity at least partially to “social determinants, which include fewer jobs, increased poverty, disproportionate incarceration, fewer educational opportunities, stigma, homophobia, and concurrent sexual networks in some Black communities” (Lanier and Sutton 2013:263). They urge the introduction of guidelines for regular, preventive health visits to physicians as one avenue through which to address this issue, but note that even more fundamental problems (i.e., lack of access to health care generally) may render their recommendations less effective than hoped. Leston et al. (2012) likewise complicate the notion of risk as it exists for another non-White population: Alaska Native youths. In exploring the
circumstances surrounding sexual risk-taking, the paper “situates” the studied group, both culturally and geographically, as well as vis-à-vis health structures. The small size and relative inaccessibility of many settlements where Alaska Native youth live, coupled with forced reliance on certain types of health care providers (many of whom figure in youth’s family and community networks) for information related to sexual health or prevention materials are listed as important elements any risk-reduction strategy must confront (Leston et al. 2012:3). Although neither paper questions the significance of risk for the studied groups (what, for example, does it mean to become pregnant as an Alaskan Native teenager, or infected with HIV as a young, African American MSM?), both convincingly illustrate its multifactorial etiology.

Indeed, a recent article by Hoffman et al. (2012) demonstrates that even classic epidemiological studies do not have to be blind to social and cultural context. These authors note that West Indian-born Blacks are typically aggregated with U.S.-born Blacks in epidemiological data, despite multiple reasons to suggest they might have different experiences and health statuses, values, resources, etc. By analyzing them as a separate group in surveillance data from New York City, statistically significant differences were found; namely, that the age-adjusted rate for incident HIV infection was higher for West Indian-born Blacks (43.19 per 100,000, 95% confidence interval [CI] = 38.92, 49.10) than it was for U.S.-born Whites and Dominican immigrants (19.96; 95% CI = 18.63, 21.37), but lower than that for U.S.-born Blacks and Haitian immigrants (109.48; 95% CI = 105.02, 114.10). The discussion of this finding included dynamics associated with migration, social support, and racism (Hoffman et al. 2012:2129).

If such analysis is surprising, given its relatively straightforwardly-quantitative purpose, it is also necessary to remember that no approach constitutes a guarantee of reflexivity or
extensive critical thought about risk. Speizer et al. (2011) purport to determine whether there is a correlation between community-level HIV risk behaviors and HIV prevalence among women and men in Zimbabwe. They claim this analysis is necessary because “Only recently have HIV research and programmatic efforts begun to consider the context within which individuals live” (Speizer et al. 2011:438)—an assertion which even a cursory glance at social science literature on HIV reveals as patently false. Based on data from the 2005-06 Zimbabwe Demographic and Health Survey, the authors find that members of “communities with more premarital sex, greater engagement in nonmarital partnerships, higher levels of [Intimate Partner Violence], and higher HIV prevalence among the opposite sex are at an increased risk for HIV compared with their counterparts in communities where the prevalence of these factors is lower” (Speizer et al. 2011:439).

The expectedness of these findings does not render this study superfluous or irrelevant. However, several issues arise upon serious engagement with the paper. First, reported behavior is treated as actual behavior; the authors never mention the possibility of response bias in these household survey data. A truly basic consideration, this idea should make an appearance, even if it is raised only to be dismissed (this omission is especially striking in a study that accords such an important role to what “communities” deem “acceptable”). Second, higher reported frequency of what the authors call “risk behavior” is conflated with greater “acceptability;” the possibility of differential acceptability (particularly between the social groups those practices serve, in part, to create and maintain) is never entertained. In short, they do not ask, “Acceptable to whom?” Further, there is a total lack of contextualization of “risk-taking behavior.” That is, there is no discussion about what other functions these behaviors might serve (which, especially for survival sex, is a relevant and rather obvious consideration) or what other options people

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32 Response bias has long been acknowledged in public health (e.g. Catania et al. 1990).
might have at their disposal; such practices are portrayed as simply maladaptive and in need of revision. This lack of attention to contingency and embeddedness allows the authors to make the blanket recommendation of simply reducing the “social acceptability” of actions that expose people to HIV. Thus, despite an ostensible focus on “community,” this study exhibits some of the much-critiqued tendencies of public health research noted previously in this review. Namely, behavior and individuals are not considered in sociocultural or historical context, and disease prevention is implicitly accorded an unquestionable priority that may diverge from the way life is experienced by the study population. Consequently, in this treatment, “risk” appears as a phenomenon constituted by the collective weight of discrete individual actions and assessments of their acceptability, which seemingly arise spontaneously.

The attempt to influence individuals’ perceptions “acceptable” behavior is behind the now relatively common practice of criminalizing non-disclosure of HIV in certain contexts. Whether these legalistic strategies function as intended—and hence the impact they have on HIV risk—has become a focus of research, two examples of which are reviewed here. Galletly et al. (2012) explore the impact of New Jersey’s “HIV Exposure Law,” while Mykhalovskiy (2011) focuses on the Canadian context. Neither study was intended as an exhaustive exploration of determinants of “risky behavior;” nonetheless, their approaches still differ markedly, which is one of the reasons they are compared here. The former study defined its interest narrowly, as the behavior and perceptions of stigma reported by seropositive individuals, and identifying what difference, if any, awareness of the law made. Galletly and co-authors pursued this objective using survey methodology (N = 479), and found that just over half (51%) of survey respondents were aware of the law. However, “awareness was not associated with increased sexual abstinence, condom use with most recent partner, or seropositive status disclosure” (Galletly et
al. 2011:2135). In addition, contrary to the researchers’ expectations, seropositive individuals who did not know about the law reported greater stigma and more discomfort around serostatus disclosure. Although some sociodemographic indicators were collected, these did not figure prominently in the discussion, nor were they used in anything but a descriptive way. Thus, sex-related risk, in this scholarly iteration, is constructed as the result of behavior between two individuals; knowledge is presumed to have a direct impact (or lack thereof) on risk. The authors conclude that, if the goal of disclosure laws is to reduce HIV transmission by minimizing sexual risk behavior, they do not appear to effectively serve their intended purpose.

A similar conclusion is reached by Mykhalovskiy, albeit through research employing different methods and foundational assumptions. Mykhalovskiy, a sociologist, conducted focus groups and interviews with both seropositive individuals and service providers, a methodological choice justified by his ontological conviction that “any effects of the criminal law on HIV prevention occur through a complex set of institutional and social processes that extend beyond the criminal law-PHA behavior dyad” (Mykhalovskiy 2011:669). Widening the analytical field of vision (and objectives of the research) in this way brought into view conflicting discourses on “risk,” and the impact this had on seropositive individuals, as well as HIV prevention counselors.

Key to this review is Mykhalovskiy’s observation that the legal concept of “significant risk” was too vague to provide behavioral guidance. Precisely how it articulated with “a more familiar and established terrain of risk discourse—public health concepts that connect epidemiological risk with particular sexual activities, such as oral sex, distributed along a gradient of no, negligible, low and high levels of transmission risk” (Mykhalovskiy 2011:671)—was unknown. One important result of this ambiguity was uncertainty on the part of seropositive people as to their legal obligations. Another was that confusion about how to reconcile
competing risk discourses led both people living with HIV, as well as counseling professionals, to perceive dangers in full disclosure during counseling sessions. A major impact of the law, then, seems to have been foreclosing potential (and formerly “safe”) spaces for requesting assistance with disclosure-related issues. The author suggests this may leave HIV-positive clients less well-prepared to navigate sexual scenarios that pose a risk to their partners, “an important example of how the criminal law’s impact on HIV prevention [and, therefore, risk] is relational and mediated” (Mykhalovskiy 2011:672). This contrast of two studies is intended to demonstrate that even when scholars research the same topic, and come to similar conclusions, their approaches to risk can be radically different.

One of the aims of this review was to identify new or unique approaches to HIV risk in the public health literature, and in this vein a few more heavily theoretical articles deserve mention. These treatments have in common their attempt to theorize the impact of inequality, both social and material, on health. Zierler and Krieger (1997) discuss U.S. women’s HIV risk from four different perspectives: feminism, political economy of health, ecosocial, and human rights. Specifically, economic and gender-based inequalities, as well as racism and heterosexism are explored as potential risks to women’s health (Zierler and Krieger 1997:411-425). Wingood and DiClemente (2000) also focus on women, and adapt Connell’s Theory of Gender and Power to explain exposure to HIV. The theory of gender and power posits a tripartite structure that produces the gender roles that women and men are expected to play. This structure is composed of the sexual division of labor, the sexual division of power, and Connell’s innovation, the structure of cathexis, which pertains to the emotional component of relationships (Wingood and DiClemente 2000:540). In their analysis, the authors address—among other issues—

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33 Still other approaches to reconciling social theory on gender with research findings on HIV risk, albeit in different contexts, are offered by Gurevich et al. (2007) and Marqués et al. (2007).
conditions like poverty, lack of health insurance or access to health care, ethnic minority status, conservative gender norms, and partner-related issues as risk factors for HIV (Wingood and DiClemente 2000:545-554). Importantly, like feminist intersectional theory, Wingood and DiClemente (2000:541) emphasize that attempts to consider the effects of any one of the three structural components in isolation are misguided.

From a Brazilian perspective, Ayres et al. (2003), theorize the concept of “vulnerability,” which has become central to epidemiological explanations in that country since the 1990s. As they explain, vulnerabilidade is also made up of three components that work in tandem: the individual, the social, and the programmatic (this last component deals with democratized channeling of resources). All of the theorists mentioned here would agree with Ayres et al. (2003:123) that one’s chance of exposure to illness “is the result of a confluence of factors that are not merely individual but collective, contextual, in which greater susceptibility to infection and illness goes together with diminished availability of resources with which to protect oneself.” To a medical anthropologist educated in the United States, this sounds strikingly like structural violence (Farmer 2004).

The insistence on the imbricated nature of risk that these treatments share also characterizes work in a relatively new area of research in public health, one that borrows the notion of “syndemic” from medical anthropology, specifically the work of Merill Singer (Singer and Snipes 1992; Singer and Clair 2003). These treatments attempt to operationalize and quantify (Brennan et al. 2012; Kurtz et al. 2012) or graphically represent (Talman et al. 2013) the concept, with variable success.34 One of the challenging but essential considerations such models must include is to situate the behavior and identity of studied groups in cultural,

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34 Friedman et al.’s (2009) treatment of HIV risk among African Americans deserves laud in this vein. Despite not employing a “syndemic” lens, serious attention is accorded the structural and social constitution of risk, with national, social/sexual network, and individual dynamics appearing in a pictorial representation of the process.
socioeconomic, or geopolitical context, especially vis-à-vis the wider society of which that group is a part (Johnson 2006). Failing this, the models lose the ability to harness the most radical implications of Singer’s concept—namely that “diseases do not exist in a social vacuum nor solely within the bodies of those they inflict, thus their transmission and impact is never merely a biological process. Ultimately, social factors, like poverty, stigmatization, racism, sexism, ostracism, and structural violence may be of far greater importance than the nature of pathogens or the bodily systems they infect” (Singer and Clair 2003:428). Finding a way to quantify these complex dynamics—as Sisyphean a task as that is—could constitute public health’s unique contribution to syndemic theory, and would unquestionably move research on “risk” conceptually forward.

**Understanding Anthropological Approaches to Risk**

As already outlined, in this section I deal with the way risk has been constructed within anthropology. The discussion is divided into three sections. Those treatments that see risk primarily as flowing from cultural ideals and discourse about gender, sexuality, and attendant power relationships (often framed in a Foucaultian sense) fall into what I call the idealist camp. A contrasting approach situates risk as produced by material (for example, political-economic or spatial) factors. Admittedly, most authors referenced material and ideational contributions to risk production; nevertheless, one orientation was usually accorded priority, which determined the source’s classification. The third section deals with work that can only be described as achieving an integration of material and ideal elements in their analyses.

**Idealist Conceptions of Risk**

One of the most basic ways anthropology has contributed to understanding the risk of sexual transmission of HIV is through the discipline’s understanding of sex as a “culturally
informed experience, shaped by the inner world and the material world in which humans live” (Parker, Herdt and Caballo 1991:79). Possible and/or acceptable sexuality varies in dialogue with and is structured by what Parker, Herdt and Caballo (1991:79) call *sexual culture*, that is, “systems of meaning, of knowledge, beliefs and practices” about sex that are shared and learned. In the Brazilian context, aspects of sexual culture relevant to this study are so fundamentally connected—through heteronormativity—to hegemonic notions of gender that discussing them separately makes no conceptual sense. As Rebhun (1999:109-110) notes, “Ideas on the propriety of sexual behavior figure among the factors that structure each gender’s perceptions of and responses to the other.” This review focuses on the way particular practices link to (or do not) sexual “orientation” or identity, the essential role of reproduction in constituting gender, and the meaning of condom use. These issues are important because—according to idealist formulations—people’s ideas about the nature of, and their normative convictions regarding reality (certain kinds of people, acts, objects, etc.) shape what they do, which in turn translates to the ways they are exposed (or not) to risk.

A striking example of this dynamic is the extensive and pioneering work of Richard Parker on male sexuality in Brazil (Parker 1987, 1991, 1996, 2001; Parker, Herdt and Carballo 1991; Parker and Tawil 1991). One of his main findings was the contrast between fairly static U.S. sexual identities (like “homosexual” and “heterosexual”) and the Brazilian emphasis on the roles taken in sexual interaction (on the importance of roles in sexual intercourse, see also McCallum 1999). Traditionally, men taking the active, or insertive, role in anal sex do not necessarily consider themselves homosexuals; Brazilian equivalents of the English words “faggot” and “queer” are reserved for the receptive partner only. This is not to imply that the role assumed by an individual in a same-sex encounter is always the same; on the contrary,
Parker (1996:150) argues that his research found a high degree of flexibility in this regard. In fact, many Brazilian men who have sex with men (MSM) continue to have, or be concurrently involved in, physical and emotional relationships with women (Parker and Tawil 1991; Parker 1996)—a finding with its own salience in terms of HIV-related risk. Though Ford, Vieira, and Villela (2003:53) are wise in cautioning that “Care needs to be taken against over-generalization regarding male sexuality in Brazil,” anthropologists are in fact attending to variation and processes of sociocultural change. For instance, Klein (1999:241) and Parker (1996:150) noted that in the late 1990s a “gay” identity was taking shape in Brazil, largely in response to the AIDS epidemic, though it was still fairly confined to larger cities (see also Garcia and Parker 2006).

Quite early on Parker’s (1987) understanding of sexual culture led him to the conclusion that cross cultural differences in sexuality would heavily impact HIV prevention efforts. Interventions developed on the basis of sexual identities, practices, and AIDS incidence among gay men in the U.S. and Europe assumed those factors to be cross-cultural constants, which they were not. These projects, directed towards a risk group of “homosexuals,” were seen as irrelevant by men who did not identify with that label. Use of foreign epidemiological categories led to a false sense of security for some individuals; in that way, such labeling can actually be said to produce risk. Similar dynamics of sexuality, risk, and prevention failure have been noted among Latinos of varying provenance both in the U.S. and in Latin American contexts, (Singer and Marxuach-Rodriquez 1996; Castañeda and Zavella 2003; Carrier and Magaña 1991) and some African American males (Whitehead 1997; Ford et al. 2007). The observation that “occasional (or even relatively frequent) same-sex interactions need not necessarily call into question” males’ self-identification as heterosexual (Parker and Tawil 1991:61) lends credence
to the more general assertion that sexuality must be examined in context to ascertain what ramifications such constructions might have for HIV risk.

The link between Brazilian women’s sexuality and HIV risk has also been explored, although—to my knowledge—this production only considers heterosexual practice. The best of this work, recognizing that heteronormativity is an integral component of hegemonic notions of gender in this context, views women’s gender and sexuality in relation to men’s (Scheper-Hughes 1992; Goldstein 1992, 1994; Santos, Ventura-Filipe, and Paiva 1998; Paiva 1995; Knauth 1997a, 1997b, 1998). Although this review shortly turns to examining dichotomously structured gender ideologies in more detail, a note about the placement of this research within the classificatory schema employed in this essay is necessary here. In general, risk of HIV transmission is acknowledged as just one among multiple risks faced, especially by impoverished Brazilian women (e.g., Goldstein 1994:919; Paiva 1995:111); these risks are situated within the broader social and economic context of the country as a whole. However, the focus of the research is on culturally specific notions of sexuality and particularly “gendered perspectives on sexuality and transgression” (Goldstein 1992:31). As such, although the authors make arguments for the relevance of political economic structures, I include their work in this section (rather than in the one on materialism) because it deals most explicitly with gendered constructions of identity within affective relationships, as opposed to analyzing gender inequality as a structural force.

The first and foundational truth about gender in Brazil is that it is partially constituted through sexual practice. Some scholars argue that women and biological males who take the receptive position in anal intercourse in fact “share a gender (not-men) because they share a desire for real men (penetrators) and a capacity to arouse desire in them. From the point-of-view
of the systematic features of sexuality in Latin America, then, this is a binary gender system that stresses corporeal action and positioning in relation to other bodies, over biological essence or 'sex'" (McCallum 1999:277; see also Kulick 1998). Whether or not this men/not-men binary structures Brazilian gender at its furthest extensions (for example, travestis), no scholarly work questions that women qua women are partially defined—and differentiated from men—by what they (should) do sexually.

At the national level, Brazil is undeniably a postcolonial (Good et al. 2008), patriarchal society (Schep-Hughes 1992; Goldstein 2003), and heteronormativity has long been enshrined in this context through the guise of complementary opposites. There is a pervasive belief that men have an undeniable and voracious need for sex (Rebhun 1999; Ford et al. 2003; Miranda et al. 2013), indeed that “male nature requires several [sexual] partners” (Kerr-Pontes et al. 2004). Urgent and irrepressible desire is seen as constitutive of maleness. Paiva (1995:101) reported the perception among Brazilian teenagers that “being a man is to possess less control over one’s sexual and aggressive impulses;” a dozen years later Knauth (2007) found that strong sexual drives, dominance, and risk-taking were still characteristics of Brazilian masculinity. Thus, masculine privilege is partly evidenced in the way men are allowed to express what ostensibly comes naturally to them: a “good” Brazilian man is abundantly sexually active, potentially with multiple partners. This perceived essence serves to justify men’s extramarital relationships, and entails a particular role for them in sexual interactions: men are “transgressors” (Goldstein 1992:29).

In contrast, although there is change afoot (particularly in urban, middle- and upper-classes and in the Southern and Southeastern regions, see Heilborn et al. 2006; Ford et al. 2003:60), women must be boundary-setters in sexual interactions, with the boundaries varying

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35 Clearly, it also has socioeconomic and political manifestations (e.g., Kerr-Pontes et al. 2004).
by their civil status. For unmarried women, female sexual innocence and passivity (in terms of her own sexual desire) are still “part of what it means to be female in Brazil” (Goldstein 1992:32). Virginity at marriage is still the ideal, followed by responsiveness to male needs afterward. Thus, “The single young woman must always say no and the married women must never say no” (Paiva 1995:101).

This “never” is not quite absolute however. As Goldstein (1992:29) writes, her female research participants “complain openly about the fact that their husbands are curious and enamored with anal sex, while at the same time claiming their own disinterest, dislike, or active opposition to it.” She acknowledges that such statements might be straight-forward statements of fact regarding women’s sexual practice, but also perceptively observes that such comments might mean “that they are as women prohibited in their talk from admitting publicly that they might like this ‘tabu’ act. In other words, we learn that a very strong double standard exists about what is sayable depending on one’s gender” (Goldstein 1992:30). It is critical to remember that, given the inextricability of gender and sex in Brazil generally, statements about sex are also performances of gender (Butler 1990) and should be interpreted in full cognizance of their potential deployment as markers thereof.

To be more specific, the qualities mentioned above are fundamental to the status of a “good” woman—she who occupies the respectable, marriageable pole of the madonna/whore dichotomy that further structures Latin American femininity (McCallum 1999:277). In Brazil, this distinction has, since at least the mid-1980s, been discussed in terms of rua (“street”) and

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36 In fact, Liguori and Lamas (2003:87) argue that “In most parts of the world, dominant gender systems” exhibit this double standard in terms of sexual behavior. On the other hand, Schatz (2005) claims that a focus on ideal conceptions of gendered behavior and power can lead researchers to miss concrete expressions of agency by women in the sexual realm.

37 This dichotomy is also more widely pervasive than just Brazil or Latin America (Liguori and Lamas 2003).
casa (“house/home”), following the analysis of Roberto DaMatta (1984). As concisely summarized by Peter M. Beattie (1996:440), the “house” evokes “honor, family, order, marriage, safety, and private power, while the street connotes disgrace, chaos, illegitimacy, danger, vagrancy, and vulnerability,” especially to male sexual aggression. Thus, a good woman stays at home, secured from both the physical predations and moral contagion of the street. Even the borders of the casa—spaces of liminality, in Turner’s (1977) use of the term—were not safe.

"A girl who 'stood at the door' [of the house] (ficava na porta) was a bad girl, in danger of losing her virginity before marriage" (McCallum 1999:280). Men, on the other hand, could go where they pleased, and do as they liked sexually, especially with women who inhabited the permissive and dangerous world of the rua.

The configuration of this system of gender is not, however, determined exclusively by orientations (e.g., active/passive, demanding/denying) to, and participation in sexual acts themselves. As Rebhun (1999:105) demonstrates, by the end of the 19th century, Brazilian hygienists, concerned with the country’s modernization, “promoted the love-based, monogamous, nuclear family as conducive to social order.” This ideal, whose spatial domain is the casa, also exerts powerful influence on both men and women. Especially for low-income couples, which in the Brazilian literature are said to be from the classe popular, or “popular class,” sexual-affective unions are key to respectable adulthood (Beattie 1996) and are solidified through the birth of children (Heilborn et al. 2006). “Couples who have no children are said to tire of each other before too long (enjoa)” (McCallum 1999:279). Thus, maternity is a very important component of femininity (Paiva 1995; Knauth 1997a; Santos et al. 1998; Santos et al. 2002; McCallum 1999; Goldstein 2003; Hopkins et al. 2005).38 But the desire for pregnancy as an outcome of a sexual relationship is not the exclusive purview of women. Men also want

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38 Again, this phenomenon is not specific to Brazil: see McGrath et al. 1992; Sobo 1995
babies, or at least receive “their passport to adult life and to manhood through becoming fathers” (Santos et al. 1998:38; Paiva et al. 2003:94; Knauth 1997b).

In addition, as McCallum (1999:286) explains, "When [a Brazilian man] can successfully act as a provider for his wife and children, allowing her to stay home, he has made the first step in the long process of social ascension." This highlights another fundamental aspect of masculinity in Brazil: the provider role, with emphasis on responsibility, respect, and reliability (Ford et al. 2003:57). The ability of any particular man to fulfill this role edges the discussion toward more structural considerations of economics (from the global to the household level)—as such, it, and other complications of “gender” by class, will be dealt with in more detail in the section on materialist approaches to risk. However, here it is necessary to note that the role of family breadwinner (which, in Brazilian Portuguese, is pai de família, or “father of a family”) is highly valorized by men across social classes (Ford et al. 2003:57) but also exists in tension with the ideal of masculine autonomy and freedom (Malta et al. 2006). In Brazilian gender ideology, "women are marked as in need of control, men as in need of freedom to act…[the man] must be free to go out and battle in the world, earn money, spend it on drinking with his mates, or on sexual adventures. To return to his condition as husband-provider-father must be his own choice" (McCallum 1999:284; for more on provider vs. masculine freedom, see Knauth 1998).

Although this depiction of Brazilian gender norms is not exhaustive, it provides the background to consider several implications for HIV risk and challenges to prevention efforts, specifically the attempt to increase condom use. In attempting to explain the lack of behavior change among largely low-income, Brazilian women in stable relationships, scholars have noted that hegemonic conceptions of femininity militate against condom use. Compliance with the mandate for feminine ignorance of sexuality constrains women from referencing condoms, since
condoms are associated with the *rua* and stigmatized sexual practices. This same mandate leaves women “unaware of or unable to openly acknowledge the sexual practices of their male partners” (Goldstein 1994:920),³⁹ which can include both heterosexual and same-sex interactions outside of the primary relationship. Indeed, requesting condom use, in addition to violating cultural expectations of female passivity, would constitute an implicit recognition of men’s extra-conjugal behavior, since, as Vera Paiva (1995:100) notes, “The condom causes feeling of strangeness; it symbolizes an accusation.” It is for this reason that such requests can constitute “a declaration of domestic war” (Schep–Hughes 1994:994; see also Lupton 1994), potentially resulting in physical violence or termination of the relationship. Also, if request must become insistence, Goldstein questions whether Brazilian women wield sufficient power within their relationships to enforce their wishes (Goldstein 1992:26).⁴⁰ Finally, given the importance of childbearing for Brazilian women, it is notable that “the vast majority of public health programs have still not taken on board the fact that (as one study participant put it): ‘Getting AIDS [sic] and getting pregnant may happen in the same sexual encounter’” (Santos et al. 1998:31). Thus, ideas about femininity—what women should or shouldn’t know, and should or shouldn’t do—directly impinge on their risk for HIV.

If the literature has thus far largely focused on the gendered dimensions of women’s HIV risk, men’s experiences in this realm are equally structured, if not equally constraining. While in a patriarchal system men are advantaged vis-à-vis women, normative masculinity nonetheless demands performance, and this performance has implications for HIV risk. As detailed above, the desire for fatherhood is too infrequently addressed as a barrier to HIV prevention. But even

³⁹ See also McGrath et al. 1992; Sibthorpe 1992; Sobo 1995; Hirsch et al. 2006; Jordan Smith 2006 on similar dynamics in other contexts
⁴⁰ This particular dynamic is not specific to Brazil, of course; see also McGrath et al. 1992 for a Ugandan example, Matshalaga 1999 for Zimbabwe. On the other hand, Schatz (2005) claims there is more space for women’s agency than typically recognized.
disregarding such important social practices as reproduction, male acceptance of sexual risk reduction techniques is antithetical to Brazilian notions about manhood (Paiva 1995, Knauth 2007, 1997b). As noted in a qualitative study of incarcerated male adolescents in São Paulo, “To put on a condom is to curb…signs of masculinity” (Peres et al. 2002)—which is to say nothing of strategies like abstinence or monogamy.

It is in light of such ideas that we should interpret the consistent finding that Brazilian men do not “like” condoms. In Peres et al.’s (2002:40) study, 60% of respondents reported that “condoms disturb sex.” Over 40% of female, HIV-positive participants in Santos, Ventura-Filipe, and Paiva’s study (1998:34) reported inconsistent condom use with partners, largely because men “do not enjoy using condoms, they believe that they can feel the woman’s orgasm and their own better without a condom.” Likewise, one of the justifications for low rates of condom use among established couples from a different region (the Federal District as opposed to Southeast, where the previous two studies were conducted) was the male partner’s dislike of the practice (Maia et al. 2008). Research participants from the Northeast region reported similar attitudes. One man said, “[With a condom], there’s no pleasure in being together. It’s a woman’s vagina against plastic.” Another asserted sex with condoms “is no fun. It’s doesn’t feel alive. It [the penis] was not made to be covered” (Kerr-Pontes et al. 2004:323). While physical sensation may indeed figure in the generalized rejection of condoms, it seems likely that many men are also—if not “instead”—refusing what they see as an emasculating practice. Condoms are tolerated only when considered absolutely necessary.

How men discern when this is the case brings the casa-rua distinction back into sharp focus. Because HIV/AIDS is still solidly associated with non-normative behavior and the Other (Malta et al. 2006; Knauth 1997), members of one’s own personal networks of family and
friends are not seen as risks. This sense of security most strongly characterizes one’s own stable partner—a person who, in DaMatta’s metaphorical terms, inhabits the *casa*. In Maia et al.’s study (2008:3), most of the sample of 200 married people (100 men and 100 women) who reported not using condoms claimed it was because “it would be incompatible with having a fixed sexual partner.” This lack of perceived risk from stable partners also seemed to characterize the participants in an AIDS risk-reduction intervention conducted by Hearst et al. (1999:77). Although reported condom use increased with “casual” partners after the intervention, it increased “less with ‘regular’ nonprimary partners, and not at all with primary partners.” In addition, in Peres et al.’s study (2002:41), adolescent males reported that, “Condoms don’t need to be used with the girls whom they are dating, just with partners they don’t know very well.” This contrast is articulated most clearly, however, by a participant in Kerr-Ponte et al.’s study (2004:322) in response to a question about whether condoms are always necessary: “I don’t think so, because if you know the partner, that she’s a *lady* [authors’ original italics], that she’s not a dirty woman, I don’t think you have to take precautions with all of them.” Thus, a “known” woman is a “safe” woman; condoms are only required with women from the *rua*.41

Strong and impervious to risk (Ford et al. 2003; Knauth 2007), according to Brazilian conventional wisdom, a “real” man has no need to dwell on health-related considerations, and no mind to do so when in the throes of sexual desire. And although Brazilian men will unambiguously state exactly this case (e.g., Malta et al. 2006:493), here we should take Goldstein’s interpretive caution about what is “sayable” to heart. While I am not arguing that Brazilian men necessarily want to use condoms but can’t, we should recognize that masculinity,

41 Another indication of “safety” reported in the literature is appearance. Beauty or an absence of physical indications of disease (extreme thinness, skin disorders, or STI symptoms) is still frequently taken to mean a person does not have HIV (Peres et al. 2002; Kerr-Pontes et al. 2004; Malta et al. 2006).
just as much as femininity, is a dictate that must be lived up to—that is, it exercises a disciplinary function. Ford et al. (2003), for instance, report that Brazilian men experience this as fear that they will not fulfill their female partners’ sexual expectations. Thus, whatever else it may be, eschewing condom use is always an instantiation of masculinity, an attempt to avoid being cast into the “not-men” category.

Importantly, however, a man who refuses condoms is not only making a statement about himself, he is simultaneously constructing his female partner as the kind of woman who poses no risk. His actions classify her as belonging to the *casa*, whereas recourse to condom use would cast her into the metaphorical street. Again, I am not arguing that Brazilian women say they want to use condoms, but really don’t. I merely want to point out that both partners succeed at normative performances of Brazilian gender through exposing themselves to sexual risk. Therefore, although there is sometimes an undertone in the academic literature that ascribes to men a cold disregard for their partners’ health, the calculus involved in decisions about sex and condom use is complex, replete with multiple meanings for men and women. In essence, as Paiva (1995:101) explains, measures to reduce risk of HIV-transmission “directly threaten the notions of virility and femininity shared by almost all the subgroups within the Brazilian population.”

The foregoing section, regarding the interconnections between gender as a social system and sex and childbearing/family formation as identity-establishing practices, focused exclusively on Brazil, as those culturally-specific influences are most likely to be relevant in the context of the research reported in this dissertation. But condom use (or, more appropriately, non-use) has, of course, been a frequently employed lens through which to approach (especially women’s) HIV risk among non-Brazilian populations as well. Many of these studies foreground
psychosociality and the meanings and importance of relationships in the production of HIV-related risk. Their findings both support and extend discussion of the Brazilian case. They also, however, frame the practice of unprotected sex by the studied individuals as risk denial (as, incidentally, does Paiva 1995:102). While this is clearly one possibility, it may prematurely foreclose the possibility of other interpretations—a point which will be considered later in this chapter.

Sibthorpe (1992) deals specifically with the potential for sexual transmission among injecting drug users (IDUs) in Oregon. She notes that by the end of the first decade of the epidemic in the U.S., social scientists had documented low rates of condom use among IDUs, as well as various barriers to protected sex (women’s lack of power in relationships, poverty, dependence on men, etc.). She acknowledges these constraints, but sees a more fundamental obstacle at work, a cognitive factor that prevented IDUs and those sexually involved with them from even perceiving the risk inherent in their unprotected sexual practices. As the barrier of choice for protection against sexually transmitted infections (STIs) of all kinds, Sibthorpe notes that condoms symbolize the kinds of sexual relationships in which danger and uncleanness (Douglas 1966) feature. Accordingly, condom use in casual sexual relationships, though a symbolic act, is relatively unproblematic. However, with reference to primary relationships, the signification of “guilt or suspicion of conduct that calls into question the commitment, attachment, and exclusivity of important social bonds” (Sibthorpe 1992:266) is too painful a challenge for those at risk to acknowledge or surmount. Thus, HIV risk goes unaddressed.

Such findings foreshadowed those of Elisa J. Sobo’s much longer treatment of AIDS risk denial among disadvantaged, mostly African-American women in Cleveland, Ohio. Sobo (1995:46) writes, “people highlight individual responsibility for preventing HIV infection and
exhibit optimistically-biased personal AIDS-risk denial.” They do this despite high levels of general knowledge about HIV risk; what’s missing is the personalization of this information. Foreman (2003:649), in her study of African-American college women’s sexual risk-taking, calls this the “affective override of cognition.” The difference in social context between the two study groups notwithstanding, similar reasons were found for this process to be operant. Sexual risk-taking (in the form of non-use of condoms) is common for three main reasons: because women desire intimacy with their partner, seek a long term relationship with their partner, or feel their or their partner’s sexual pleasure will be inhibited by condom use (Foreman 2003:645-649). Sobo also draws attention to the fact that unsafe sex figures into pervasive “cultural ideals for heterosexual relationships,” explicitly (although perhaps not entirely convincingly, se Kammerer 1999:130) discounting the recourse to unprotected sex among her Cleveland informants as an economic strategy (Sobo 1995:75-102).

The “risk denial” that facilitates unprotected sex is based, according to Sobo, on a set of narratives, examples of which are also found in the work of Sibthorpe (1992:264), Foreman (2003:645) and are even employed by men in Jordan Smith’s (2006) examination of the changing nature of intimate relationships in Nigeria. The Monogamy Narrative describes the previously mentioned, “idealized, monogamous, heterosexual union…that brings the most status and esteem” (Sobo 1995:115) to the women who claim to have achieved such a relationship. An essential discursive support to having attained this ideal is “talk and action that supports a belief in one’s own ability to identify ‘clean’ (disease-free) and ‘conscious’ (honorable) men” (Sobo 1995:113) with whom to establish a relationship; this is called the Wisdom Narrative. Thus, women are conversant in safer sex discourse, and in certain circumstances may voice or even
embody it, while in others the pursuit of social and affective needs takes precedence and produces risk denial.

In general, I argue that the work grouped here is idealist in that it focuses on people’s struggles to achieve ideals—culturally-specific or context-bound as they may be. Power and discourse are key explanatory components, and particular notions of risk derive from such an approach. Risk is seen as relationally produced, through practice that is performed according to—or at least with implicit reference to—cultural logics. This kind of risk is inherently dialogic (Bakhtin 1984), in that it is structured by and undertaken in response to particular cultural expectations that characterize the context of its production. The locus of risk then is between a subject and hegemonic discourse, with or without another subject as an interlocutor. This contrasts sharply with more materialist versions of risk, as I will argue below.

**Materialist Conceptions of Risk**

By classifying anthropological treatments of the risk of sexual transmission of HIV into an idealist-materialist dichotomy I am aware of inviting criticism and charges of classificatory arbitrariness. Nevertheless, while the exact placement of the dividing line may be a fuzzy no-(hu)man’s land, two principal differences are paramount and have been used as guideposts. In general, authors in the materialist category attribute causality differently than the idealists, namely by grounding observed phenomena in political economy. As Schoepf (1991:750) unambiguously states, “disease is socially produced…[it] is amplified and given direction by the social forces set in motion by economic change.” Though both sections contain work on condom use, for example, the explanatory models used by Sibthorpe (1992) and Paiva (1995) mention socioeconomic context but privilege gender ideology. The article by Knauth et al. (1998) reverses those priorities. This section is somewhat artificially truncated, since I take up some
more recent work that accords priority to material factors in a later section on commodification. Other examples, in the subsequent “Integrations” section, strike more of a balance, impressively linking “individual life stories with larger social processes out of the control of most people” (Waterston 1997:1381).

In addition to the emphasis on political economy, another important distinguishing approach is the materialists’ tendency to urge a “historically deep” analysis (Farmer 2004:309). The above citation from Schoepf (1991:750), referring to Central Africa, is, for instance, immediately preceded by the statement, “Colonial penetration often spread disease, altered the ecology, disrupted social relations and created major public health problems.” A long section then details epidemics of tuberculosis, trypanosomiasis and schistosomiasis catalyzed or exacerbated by colonial governments. Likewise, the history of labor migration figures in the work by both Hirsch et al. (2006) and Romero-Daza (1994).

One of the most interesting turns to history and political economy among the anthropological pieces considered here is Jessica Gregg’s (2006) examination of love and sexuality in a Brazilian favela (shantytown). Gregg cites Deniz Kandiyoti’s “patriarchal bargain” as the basis for traditional gender ideology in Brazil that involves “male support and protection of women … exchanged for control of female sexuality and appropriation of women’s labor and progeny” (Gregg 2006:158). She argues that this bargain was sustained and sustainable as long as men controlled sufficient resources to provide for families—which, in low-income areas like favelas, is usually no longer the case, offering a cogent example of the ways gender is complicated by class. In response, some favela women have renounced hope of male economic support and, seemingly, even the desire for long-term male companionship. Gregg (2006:161-163) draws on the interrelated history of “glocal” sugar markets and (physical)
environmental conditions at the regional level to posit economic and ecological changes as catalyzing the production of a place where, for many women, love seems an impossibility and sexual and social *liberdade* (freedom) takes priority (a phenomenon also present, albeit in a different context, in Castañeda and Zavella 2003:137). The preeminence of material factors is exemplified by Gregg’s statement (2006:172), “Only women who had no male commitment to lose were willing to throw away male approbation.” The particular confluence of lived experience and materiality that enables this response to gender ideology, as well as its implications for HIV risk, deserves more investigation, but it is a needed note of dissent to the idea that economic subsistence and solidifying affective relationships are all-important goals for women.

Hegemonic gender ideology, especially as it is seen to structure social inequalities, is an important component of the concept of structural violence. The overriding concern of those employing this approach is to ask “how large-scale social forces influence unequally positioned individuals in increasingly interconnected populations” (Farmer 1996:259), and thus shape risks of infection and access to treatment. Paul Farmer’s work on HIV/AIDS in Haiti is among the best-known examples of this perspective among non-anthropologists, but other scholars have brought similar analyses to bear in work with U.S. populations. Merrill Singer’s work in Critical Medical Anthropology and specifically on “syndemics” (1994, 1998; Singer and Snipe 1992; Singer and Marxuach Rodriguez 1996; Singer and Clair 2003; Castro and Singer 2004; Rhodes et al. 2005) has already been discussed, but his analysis of HIV risk as structured by poverty, racism, poor nutrition, substance abuse, etc. cannot go unmentioned here.

This multifactorial etiology also describes what Waterston (1997) found in her research at Woodhouse, a supervised, transitional, communal residence in Manhattan. She asserts, “HIV
risk and barriers to risk reduction for women like those who reside at Woodhouse have as much to do with economic necessity, the lack of affordable and adequate housing, limited access to preventive health and mental health care, and the consequences of institutionalized care as they do with individual deficiencies and limitations” (Waterston 1997:1387). Unfortunately, the author claims that, instead of seeing the constellation of socioeconomic constraints that predispose certain kinds of women (mostly homeless, mentally ill, from ethnic minority groups) to become residents of Woodhouse, public health authorities focus on the effects of those constraints and speak of “problem populations.” Like all risk group discourse, this construction does not acknowledge that such groups “are situated within the larger political economy, their experiences shaped by processes of capitalist development, state-control policies and dominant cultural ideologies” (Waterston 1997:1383). Political economic analysis does acknowledge such situatedness, and employing this framework can have radical implications: instead of focusing on “the poor” (i.e., their “lifestyle choices” like diets, levels of physical activity, and “risk” behaviors) as the problem, “poverty” becomes the locus of risk.

Poverty can also be linked to stigma. Although many considerations of stigma are predominantly psychological—and hence ideational—Paul Farmer disagrees, citing stigmatization as among the “adverse outcomes associated with structural violence [that]…come to have their ‘final common pathway’ in the material” (Farmer 2004:308). Specifically, Castro and Farmer dissent from the notion that the stigma attached to HIV/AIDS in Haiti is a cultural factor, and hence resistant to change (2005:53, 56). Instead, they argue that such stigma results at least partially from political decisions and the scarcity of resources.

Scarce resources contribute to stigma in a different way in Dickson-Gómez et al.’s (2006) study of childhood sexual abuse (CSA) and subsequent crack use and commercial sex work in El
Salvador. Instead of the consequences of poverty creating AIDS stigma, in this case, the context of poverty produces stigmatized identities that are themselves risk factors for HIV. In interviews with 40 women in the Salvadoran capital who either use crack or sell sex, 28 were found to have experienced CSA. The psychological effects of this experience, including stigma, were profound, and were due to discourses on gendered sexual culture, especially the mandate of female virginity until marriage (Dickson-Gómez et al. 2006:557). The authors hypothesize that feelings of being “already ruined” combined with “a context of extreme poverty in which other options for survival are limited” lead young women to sex work (Dickson-Gómez et al. 2006:552).

As explained by the interviewees, sex work placed these women even farther outside the bounds of acceptable behavior for honorable females, increasing their psychosocial distress; many of them turned to drugs as a coping strategy (Dickson-Gómez et al. 2006:563). Both addiction and the tendency of addicted female CSWs to work in a street context (usually after eviction from the relatively safer socio-spatiality of brothels, Dickson-Gómez et al. 2006:563) then augmented these women’s already considerable vulnerability. Thus stigma is implicated in HIV risk, but itself derives from poverty at two key junctures. The psychological and social effects of CSA may contribute to the “election” of sex work, but poverty, especially the inability to support one’s dependents, is seen as a more important background factor.42 A more distal influence of poverty was found in the socio-spatial context of the original abuse and its discovery. Perpetrators were often male family members living in close proximity to the victims and on whom key would-be protectors (usually mothers) relied financially. “The inability of families to protect daughters from CSA occurred in a context of residential overcrowding and in

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42 This is so because even women who did not experience CSA had turned to commercial sex work out of economic necessity (Dickson-Gómez et al. 2006:563).
which women were dependent on men…economically or for their housing” (Dickson-Gómez et al. 2006:568). Socially, there was no one else for victims to turn to for support; spatially, there was no safe place to which they could escape.

Spatiality also figures in some materialist approaches to HIV risk in Brazil. Lippman et al. (2007:2464), in their rapid assessment of “HIV-related services and the social context of HIV/AIDS” along Brazil’s border find the governmental response to HIV/AIDS, so often lauded internationally, to be all but invisible at the six study sites. Lack of training and even basic supplies for clinicians is seen as the material effect of politicized spatiality—needed resources do not reach frontier sites, seen as only tenuously national. Though these material constraints are not the exclusive focus of the paper, they contribute to the conceptualization of risk as an enduring characteristic of the socio-spatial environment.

Although more “fluid” than in Lippman et al.’s study, sociospatiality is also important in Knauth et al.’s (1998) description of the banalização or “banalization” of AIDS. Focusing on the discourse and behavior of those living in a neighborhood with an extremely high incidence of AIDS deaths, Knauth and co-authors show that participation in social networks characterized by elevated seroprevalence levels can lead to conceptualizing AIDS as “something normal, even banal…something that can happen to anyone” (1998:193). Rather than emphasizing the need for prevention, however, the experience of seeing people live with the virus tends to diminish the concern with infection, leading to greater risk of transmission (Knauth et al 1998). Seen this way, while risk is also cognitive, it is primarily material and structural, in that varying perceptions are grounded in the physical configuration of urban places.
Integrations

This leads to a discussion of anthropological work that defies easy placement in the idealist-materialist dichotomy. These pieces are derivative of a theorization of risk as irreducible to either “historically given and economically driven” (Farmer 2004:317) macro-level social inequalities or the micropolitics of discursively structured and emotionally charged interpersonal practice. Instead, risk is produced in the interplay of the material and ideal aspects of lived experience, neither of which can be understood in isolation.

There are striking similarities between previously considered pieces by Sibthorpe (1992), Goldstein (1992, 1994), Sobo (1995) and Foreman (2003) and Hirsch et al.’s (2006) exploration of how changing constructions of marriage contribute to HIV risk. All of this work employs an idealist conception of risk, in that ideals and beliefs about relationships impact behavior in those relationships. In the case considered by Hirsch et al. among Mexican women in both Mexican and post-migration U.S. contexts, a shift has occurred in marriage ideals, from *respeto* (respect) to *confianza* (trust/intimacy). Previously, a man’s primary obligation to his wife was “first and foremost financial support and secondarily some measure of respect, his sexual behavior was largely his own concern” (Hirsch et al. 2006:104). Younger women, however, now frame fidelity in much the same way informants in other condom use studies do—as an ideal and proof of love and trust. And since, as noted in other contexts, “every act of sex without a condom is a mutual performance of trust” (Hirsch et al. 2006:109), condom use becomes an admission of betrayal, making it highly unlikely in marriages allegedly based on *confianza*. Recourse to Sobo’s (1995) “Wisdom Narrative” is evident in women’s attempts to paper over sex-related risk of HIV.

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43 In the interest of transparency, I should acknowledge that Hirsch’s work could be classified as either anthropology or public health—the only approach about which I could unreservedly make such an assertion.
transmission; as one of Hirsch’s informants stated, “I don’t worry about [my husband having extramarital affairs] because he seems like a good guy” (Hirsch et al. 2006:101).

What distinguishes Hirsch et al.’s work from the others, however, is the interdependence of psychosocial and material factors. HIV risk for women in western Mexico cannot be divorced from their husbands’ labor migration, “which is itself a product of the political and economic relationships between the United States and Mexico” (Hirsch et al. 2006:99). Labor migration of Mexicans to “El Norte” has a long history, as does (usually male) migrants’ infidelity to partners left behind. As such, responses to this behavior also have a history and form part of the repertoire of western Mexican womanhood. Non-confrontation has been and remains the norm, and infidelity does not typically justify the termination of a marriage. The exception to this rule occurs exclusively among the few women who are not dependent on a husband’s income, the majority of whom have migrated to the U.S. (Hirsch et al. 2006:106). Thus, relationship ideals are important, but they are situated firmly within a larger political economic framework.

The political economics of labor migration also figure in Nancy Romero-Daza’s study of women and AIDS in Lesotho. The dearth of economic opportunities in Lesotho necessitates the out-migration of men, usually to work in the mines in South Africa, an area of elevated HIV prevalence. It is exceedingly difficult for families to migrate together, and men often stay there alone for considerable periods of time, sometimes without sending any remittances home. Thus women, who are legal minors in Lesotho, become responsible for sustaining their families with even fewer possibilities for self-sufficiency at their disposal than men had (Romero-Daza 1994:200).

Political economy combines with cultural constructions of sexuality to produce HIV risk behaviors that, though identical from an epidemiological point of view, are seen as quite
different. Though both practices are predicated on extended separation of conjugal partners and involve the exchange of sexual favors for material benefits outside of a primary relationship, only one is considered “prostitution.” At the mines, many men form relationships with CSWs that may conform to Euro-American epidemiological expectations: a relatively anonymous transaction of short duration, involving sex for money. Then again, they may engage in a practice called *bonyatsi*, which, although it denotes the “exchange of sexual favors for either money or basic necessities” (Romero-Daza 1994:199), isn’t considered commercial sex work. *Bonyatsi* is associated with poverty, “usually implies a long-term relationship” (Romero-Daza 1994:199), and is seen as a woman’s last, best hope in dire economic circumstances.

Nonetheless, legal and economic factors are not the only reasons cited for engaging in *bonyatsi*. Affective motivations (derived from cultural constructions of person- and couplehood) are at play as well, including companionship and revenge upon husbands who have extra-marital sexual relations while away from home. As one informant said, “You do [*bonyatsi*] for the money or just to make your life interesting” (Romero-Daza 1994:200). Given the variety of purposes it serves, *bonyatsi* might be seen as an interface between the material and ideal aspects of reality.

Thus far, the migration associated with HIV risk has been male migration. Castañeda and Zavella (2003:127), however, discuss migrant Mexican women’s experiences with the “processes of racialized, gendered sexuality that constitute what Rayna Rapp calls a ‘political economy of risk’ (2000).” Undertaking farmwork in California creates risk for these women that is at once material and ideational. Material factors include work in unsupervised groups, in postures that make their bodies physically accessible, usually for low wages (certainly lower if they are undocumented) and without health benefits. These conditions grow out of and serve to
reify spatialized notions of appropriate femininity and sexual availability, as well as background discourses that construct certain ethnic groups as appropriate for certain kinds of work. In this case, Mexicans are understood to be “good for” poorly remunerated agricultural labor (for analogous discourse in industrial settings, see Yelvington 1995 in Trinidad, and Root 2006 in Malaysia), and women are discursively marked as sexually available, since by doing the same work as men in public, mixed-sex settings they do not comply with expectations of seclusion within the domestic sphere (Castañeda and Zavella 2003:128, 134).

Migrant Mexican women’s response to their new context is likewise material and ideational, in that it understands the body as simultaneously physical and symbolic. They cover their bodies and forego the use of markers of femininity (like makeup) at work, dodging risk through selective “masking” (Castañeda and Zavella 2003:135-137). Risk, however, is not something to be avoided at all costs; it is seen as the flip-side of economic gain and personal empowerment. As such, when bodily displays of femininity are deemed to offer sufficient opportunity for fulfillment, women employ them to their benefit, albeit while pushing discursive boundaries (Castañeda and Zavella 2003:140).

Thus, in these treatments of HIV risk, the body is revealed as a primary site from which to negotiate the meeting of meaning with materiality. It is also, however, the medium through which we experience reality and are acted upon by external forces, as well as a metaphor for human collectivity. As such, it is seen as a locus of both agency and constraint, an interpretation that often owes much to Scheper-Hughes and Lock’s (1987) conceptualization of the body (individual, social, and the body politic). The integration of materialist and idealist conceptions of risk was perhaps an inevitable outcome of the dialectic nature of anthropological inquiry, and
has enhanced our understanding of why and how HIV continues to be transmitted, but its most important contribution has been to open a new flexibility in thinking about risk itself.

**Commodification**

Cutting edge research in social science takes into account the entire context of an individual’s life and attends to risk’s “highly variable sexual, cultural, economic, and political significances” (Root 2006:323). One manifestation of this attention is a body of work that focuses on the exchange value of risk, whether psychosocial or economic. While all of these publications may be subsumed under a broad heading of “commodification,” they are highly diverse in terms of the specific population and context of study, as well as theoretical orientation. Only a few of the most notable trends can be explored here.

Sharp (2000) notes that commodification of the human body has a long, and culturally varied history. Consequently, anthropological interest in the subject is not new. There do seem, nonetheless, to be at least two important differences between current treatments of commodification and the examples explored in Sharp’s article. First, and perhaps obviously, there has been an increase in what is considered commodifiable. Our biomedical knowledge about the body has grown exponentially in the interim, and neoliberal logics that encourage privatized exchange of all sorts of things have, arguably, solidified a position of ascendancy. Second, and perhaps more subtly, there is a shift in the way scholars tend to conceptualize these transactions. Sharp, and many of the authors whose ideas she discusses, foreground and worry over the objectification (dehumanization) that is said to necessarily precede commodification (Sharp 2000:290), and see such dynamics as largely imposed on people by powerful structures.44

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44 To some extent the same can be said for Timmermanns and Almeling’s treatment of objectification, standardization, and commodification in health care; however, they note, “Variation in the social processes of commodification means that [scholars] cannot assume that there is [only] one paradigmatic version” (2009:25).
In contrast, although some of the difference might stem from diversity of context (Sharp does not discuss commodification in relation to HIV), the work considered here—while certainly not dismissive of larger structures—accords ample analytical space to agency. In some cases, though by no means all, commodification is portrayed as a chosen or innovative way of participating in social life.

Especially in the last decade, the anthropological literature abounds with work on commodification taking place around HIV. To offer merely a handful of examples, Anagnost (2006) and Jing (2006) both examine the commodification of blood as it relates to HIV/AIDS in China. Bhana and Pattman (2011) discuss the role of commodification of/in love and how this structures exposure to HIV among young people in South Africa. In a wide-ranging consideration of the intersection of HIV/AIDS and conflict, it is the commodification of women’s bodies—both before and after armed hostilities in Burundi, for example—that is cited as significant (de Waal 2010). In the far less violent context of HIV-related discussions in Catholic and Pentacostal settings in Brazil, it is adolescents who are commodified, often in terms of the contribution they can make to religious institutions (Muñoz-Laboy et al 2011:660).

Other studies examine a highly specific commodification: the risk of contracting HIV. This dynamic emerged from research on the practices of self-described “bug chasers” and “gift givers,” MSM who want to become infected with HIV and those who are willing to infect them, respectively. As documented by multiple scholars (e.g., Gauthier and Forsyth 1999; Freeman 2003; Tewksberry 2006; Moskowitz and Roloff 2007; Reynolds 2007), these sexual interactions may be described as the eroticized exchange between male sex partners of bodily fluids recognized as potentially infectious; the transactional aspect of these practices is made explicit in the label adopted by seropositive participants (“gift giver”).
Although Tewksberry (2006:393), following Gauthier and Forsyth (1999), poses bug chasing as “a confusing and misunderstood form of deviance,” Gregory Freeman, who arguably brought the phenomenon to popular consciousness through his article in Rolling Stone magazine, is more of a relativist. He portrays his interviewees as members of a subculture that “celebrates the virus” and imagines bug chasing as a means of becoming integrated into a supportive community (Freeman 2003). Moskowitz and Roloff (2007) specifically differentiate bug chasers from “barebackers.” While barebackers are MSM who pursue unprotected anal intercourse (UAI) as an end in itself, bug chasers (who can be further classified into “apathetic” and “ardent” types) engage in UAI also, or principally, as a sexual vehicle for HIV exposure. Such literature is important to this review primarily because it constitutes an early and profound break with typical understandings of HIV risk. Instead of assuming risk to be undesirable, avoided to the extent possible, these authors must acknowledge the positive meanings attached to HIV risk and infection: bug chasers get HIV on purpose.

Heterosexuals do not, based on the academic literature, appear to engage in similarly motivated practices. Nonetheless, a similar, critical engagement with research participants’ own articulations of the diverse circumstances that structure their lives has led some scholars to greater reflexivity with respect to the meaning of risk. Among heterosexual study populations, these “newly-visible” relevant circumstances are frequently economic, with impoverished groups garnering much scholarly attention in this regard. Given the fact that, in some contexts, seropositive people qualify for access to services and material benefits, HIV/AIDS becomes, in essence, something that can be “traded”—the definition of a commodity. Two of the earliest

45 As was previously mentioned, however, anecdotal evidence from biomedical practitioners at the fieldsite for this research (fieldnotes, June 2007) suggests that some heterosexuals might engage in behavior that would earn them a classification as “apathetic bug chasers” (Moskowitz and Roloff 2007), and non-sexual motivation for desiring transmission has been documented (e.g., Leclerc-Madlala 2009:253, see below) in non-Brazilian contexts.
examples of this type of analysis both focus on ways this potential exchange impacts participants in unexpected ways, albeit in vastly different contexts. Crane, Quirk, and van der Straten (2002) report data from interviews with 33 HIV-serodiscordant couples in California, many of whom were low-income, homeless or in danger of becoming so, and had a history or current pattern of substance use. Many also had other health problems, or lived in conditions they perceived as more threatening than HIV. As one participant put it, “Hey, I live at [street name] and [street name], ok? I have more of a chance of getting shot by drive-by than from me dying of [HIV]. For real” (Crane et al. 2002:1117).

However, due to the inclusion of HIV/AIDS in the eligibility guidelines for some government assistance programs the authors note that, actually, many of these disadvantaged couples “were living in a world in which a positive HIV antibody test or an AIDS diagnosis could result in an improved quality of life…. [and] the diagnosis appears to become more ‘valuable’ as the disease progresses” (Crane et al. 2002:1115, 1122). Some interviewees, dependent on public assistance, were aware of this exchange value. Christopher, for example, refused medical treatment for 18 months to ensure his CD4 count was low enough to secure his access: “Like I used to tell everybody, I would rather expire before that check expires. That was my whole attitude, period. I don’t want to be around without that check, I’d rather die first” (Crane et al. 2002:1122). While Crane and co-authors acknowledge that Christopher’s case was “extreme,” it poignantly illustrated a more general trend observed among their sample, and led them to suggest that “the most economically disenfranchised segments of society may be…experiencing AIDS both as a threat and as a means of survival.” (2002:1116)

Seropositivity as a conduit to improved living conditions also figures in Abadía-Barrero’s (2002; Abadía-Barrero and Castro 2006) analysis of two years of fieldwork with children in
Brazil. He studied two different groups: children who, seronegative (or undiagnosed), live on the streets and/or at a state-run shelter, and those affected by the epidemic, whether infected or orphaned by AIDS, who can therefore live at a type of NGO called a *casa de apoio* (“house of support”). He argues that nation’s impressive response to HIV/AIDS (including guaranteed treatment through the public health system and civil society mobilization to provide for other needs) had an undeniable impact. However, occurring in the midst of “profound levels of poverty and inequalities,” this created a situation in which “having AIDS and being an orphan can become desirable life conditions for Brazilian children, given that the ‘AIDS and orphan’ category brings social advantages out of reach for the majority of their peers” (Abadía-Barrero and Castro 2006:1221). All of the children in the sample had similar backgrounds that included “abandonment, exclusion, social inequality and poverty” (Abadía-Barrero 2002:418). They often came from the same *favela* neighborhoods, occasionally even the same extended family (Abadía-Barrero 2002:421). But those who are “suffering” from HIV/AIDS and in the care of NGOs receive better education, health care, and nutrition. Abadía-Barrero notes, “It could even be said that [they] have better life options than the majority of poor Brazilian children,” and quotes the aunt of a child who lives at a *casa de apoio* as saying she could “only be thankful and happy that [her nephew] is [there]. I can’t offer what he has here.” (Abadía-Barrero 2002:420).

The commodification of HIV/AIDS has created what the author calls “the greatest contradiction:” “Children with AIDS have future options, while street children, who are healthy from a biological stand-point, see no future and have as potential life outcomes illegality, exclusion and early death” (Abadía-Barrero 2002:418). It seems to fair to ask, under such conditions, what does “risk for HIV” really mean?
More recently, research conducted in Tanzania and South Africa has likewise examined the role of state support for seropositive people in contexts of extreme need. These treatments make it clear that both the amount or degree of support available, and the social environment in which that support must be sought influence conceptions of risk. Boesten (2011:781) emphasizes the interplay of poverty, overwhelming stigma, and the “structure of the AIDS industry” to understand that way “poor people living with HIV/AIDS in Tanzania…navigate a myriad of actors, agencies and organizations to obtain the aid they need to survive.” Although accessing ARV treatment became possible for people living in the research site between 2005 and 2007, the stigma surrounding HIV was still so severe that many people, including some religious leaders, “believe that the lives of HIV-positive people should not be extended as it would increase the likelihood of the infection spreading” (Boesten 2011:790). Seropositive individuals in the community have also experienced targeted aggression, which means most of them hide their status, “unless they [have] no other choice” (Boesten 2011:795). In this context, it is not surprising that those receiving treatment engage with it as “an opportunity to resume a ‘normal’ life, to adapt back into society instead of continuously facing discrimination due to the stigma attached to HIV/AIDS” (Boesten 2011:791).

However, “normal life” in this community frequently includes grinding poverty. The precarity of response to such social conditions (which the epidemic both takes place within, and helps to create) means that most seropositive people are also concerned with obtaining economic assistance. This concern engendered angry, dismissive attitudes on the part of those responsible for program administration in the area, and responses to the effect of “AIDS is not a project” (Boesten 2011:783) were common. Serostatus thus provides—i.e., can be traded for—a possible, but by no means guaranteed, avenue to subsistence. Boesten (2011:782-87) argues this
creates competition that is ultimately corrosive not only to the seropositive “community” (which, in any case, she describes as a notion problematically transplanted from other contexts), but the larger community as well.

Competition for access to serostatus-based resources is also described as intense in South Africa. At stake is a “disability grant,” the value of which was estimated, in 2005, to be twice the median income of Black South Africans (Leclerc-Madlala 2009:250). Based on participant-observation and interviews with HIV counselors and seropositive participants of support groups in Durban, Leclerc-Madlala (2009:429) illustrates how “an HIV or AIDS diagnosis in the context of entrenched poverty may represent both a threat and a means to financial survival.” Echoes of Crane et al. (2002) are present even in the detailed findings of this study: “many” poor recipients of government assistance reported they would “rather die than lose their disability grant” (McCalla-Kay 2005, cited in Leclerc-Madlala (2009:449). This source of support was fervently sought-after, but eligibility (aside from seropositivity) was ill-defined, and left to the discretion of doctors. Although the “scientifically justified” CD4 count of 200 was a widely reported benchmark, in areas of particularly high demand, other logics led to the application or consideration of more restrictive criteria of CD4 < 50 or even < 20 (Leclerc-Madlala (2009:252). This ambiguity, coupled with desperate need, led to several strategies for maintaining or securing access to the disability grant. For those who were already infected, these included bribery of physicians, and intermittently suspending treatment to produce a drop in CD4 count just prior to the bi-annual blood work that would re-certify a recipient’s eligibility. A practice called “trading in blood” was also reported, which involved paying a current grant recipient to “stand in” for a petitioner when blood that was to be submitted for testing was drawn (Leclerc-Madlala 2009:252-254). From those not yet infected, counselors reported increasingly frequent
angry reactions to negative test results, coupled with growing demand for repeat testing. In two cases, young mothers were said to have explained unprotected sexual contacts by an intention to seroconvert (Leclerc-Madlala 2009:251, 253). The totality of these practices clearly demonstrates that HIV, and even particular serological measurements, are conceptualized as commodities to be traded for a better life. In another impoverished region of the country, “testing HIV-positive is sometimes referred to as ‘having won the lotto’” (Leclerc-Madlala 2009:252). Hence, the question bears repeating: under such conditions, what does it mean to talk about “risk” and HIV/AIDS?

After a decade of work with a similar population, João Biehl’s answer to that question is, in Brazil, AIDS has become a “mode of claiming citizenship for the previously disenfranchised” (Biehl 2007:121). More specifically, the marginalized can gain access to social and political rights by appropriately asserting, and assuming the responsibility to care for, their diseased biology. This is what Biehl terms “patient-citizenship” (2007:135), but it is, in his rendering, neither automatic nor easy. As he explained in an early essay on the subject: “specialized health care is provided to those who dare to identify themselves as AIDS cases in an early stage of infection at a public institution and who autonomously search (they literally have to fight for their place in the overcrowded services) for continuous treatment” (Biehl 2004:120). Biehl’s “patient-citizenship” is closely related to Adriana Petryna’s (2002) “biological citizenship;” both ideas share a genealogy that includes Paul Rabinow’s (1999) “biosociality.” They have much in common as well with Rose and Novas’s (2004) discussion of the concept, also termed “biological citizenship.” Slightly different are Robins’s (2004) “health citizenship” and Vinh-Kim Nguyen’s (2004, 2010; Kim et al. 2007) “therapeutic citizenship,” both of which were developed in the African context.
The relationship of this now-burgeoning body of literature to treatments, like Crane et al.’s and Abadía-Barrero’s, that focus more specifically on commodification has not been addressed in these seminal works on various forms of biomedically-mediated citizenship. On one hand, it might be argued that any attempt to obtain goods, services, or even social inclusion through one’s serostatus entails a type of commodification. On the other hand, the connotation of words like “citizenship” and “(human) rights” (which frequently co-occurs) has the effect of sublimating this process of seeking, somehow removing it from the mundane realm of “exchange.” In addition, although also only sporadically emphasized by these theorists, the complex, multiple meanings of “citizenship” (Rosaldo 1994; Ong 1995, 1996, Holston 2008) suggest there are at least two aspects of the phenomenon that must be considered. The first is the material, objective, active dimension that is foregrounded by the “claiming” and “searching” in Biehl’s definitions above. This may be compatible with actions like those taken by the seropositive participants in Crane et al.’s study, as they attempted to claim disability (SSI) payments from the state on the basis of HIV/AIDS. The other aspect, however, is ideational, has to do with questions of identity and belonging (Rosaldo 1994:57), and can be expected to tap into “subjective and contradictory experiences” (Ong 1996:737). On this count, experiences and practices of, for example, patient-citizenship, may be qualitatively different from those associated with commodification, a difference that may well impact conceptions of risk. This consideration seems to lie behind a growing number of publications that respond to the citizenship literature with ethnographically-informed critiques, and propose “clientship” as an alternative explanatory concept (Meinert et al. 2009; Beckmann and Bujra 2010; Richey 2012).

The intricacies of these arguments lie beyond the scope of the present chapter, but will be presented where needed for analysis of data reported in this dissertation. At present, it is
sufficient to mention the citizenship literature because it, like approaches that focus on commodification, theorizes HIV/AIDS as, in some sense, polyvalent. Although the virus only binds to CD4 receptors within the individual human body, there are multiple sites at which the virus can attach to the body social (Scheper-Hughes and Lock 1987) and the particular “binding site,” in terms of, for example, gender, class, relationship context, geopolitical positionality, makes a difference in what infection means. This, in turn, has implications for risk, when risk is seen as a set of grounded practices (Root 2006:323), or as a “constitutive [element] of contemporary power and economic practice” (Zaloom 2004:365), as it is in the work reviewed in this section. It’s worth noting that the vast majority of the literature considered thus far, insofar as it deals with risk, approaches it hypothetically, non-specifically. While this is important, HIV-serodiscordant couples find themselves in a different situation, which may be expected to present its own contingencies and challenges. A brief exploration of scholarly production on serodiscordance is therefore offered below.

**Serodiscordant Couples**

HIV-serodiscordant couples have, since sexual contact was identified as a key mode of transmission for HIV, been widely recognized as constituting, virologically speaking, a special risk environment. For many studies, such as those concerned with estimating overall infectivity of HIV, or comparing modes of transmission, inclusion of such couples in the research design has the effect of “stacking the deck,” that is, making the exposures or events of interest more likely. In these cases, the “exposure” is understood to be identical to that which would occur in a non-(serodiscordant-)couple environment. Other studies (and this dissertation falls into such a

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46 Of course, there are ethical issues with these kinds of studies, in which investigators are interested in participants engaging in risk behaviors, or seroconverting, but for that reason the research design often includes an intervention targeted at making those events less likely than they would be outside of the study environment. It is because these couples receive something (e.g., counseling, skills training,
category) understand serodiscordance as “making a difference” and, as such, it is part of what is investigated. This type of research is often focused on how perceptions of HIV risk, justifications or frequency of exposure, or personal and dyadic identities are impacted by the sexual-affective context (that is, serodiscordance) in which they occur. Although work on same-sex male couples constitutes an important contribution to both strands of research detailed above, and this work is frequently cited (e.g., Remien et al. 1995), in light of the focus of my dissertation, the studies reviewed here deal exclusively on heterosexual serodiscordance.

De Walque (2007:502) notes that most studies of serodiscordance are from “the medical literature,” and I do not address that research here. I deal briefly with work that may be categorized into three broad foci: descriptive epidemiology, reproduction, and explanations for risk behaviors. I then discuss in greater detail studies that examine the lived experience of serodiscordance. Throughout this section, there are at least two potentially relevant socio-temporal divides that demand cognizance. I characterize them as “socio-temporal” because they not only are based on the history of the epidemic—and, more precisely, discoveries relating to its biomedical management—but also when key events in that trajectory became relevant in any particular social context. The first falls after the discovery of protease inhibitors in the mid-1990s. Whenever and wherever HIV-positive individuals have gained access to the new therapies (and it should be stated: this is not yet a reality for all seropositive people), as mentioned earlier in this chapter, living with the virus has suddenly presented new possibilities, with potentially profound implications for intimate relationships. The second divide falls after 2008 and the publication of the consensus statement of the Swiss National AIDS Commission. Controversial at the time, the “Swiss Statement” argued that, after 6 months of treatment, if medical care) as part of their participation that they become something more than merely a convenient study population (which might be seen as problematic, in terms of the basic ethical principle of justice).
viremia is undetectable and no other STIs are present, there is a negligible risk of HIV transmission (Garnett and Gazzard 2008:270). The implication for certain serodiscordant couples, of course, was that condom use would no longer be necessary. Although very little research has been published about the impact of the Swiss Statement on HIV-serodiscordant couples (but see Persson 2010, 2012a), the ideas it contains may nonetheless constitute a paradigm shift, if—bolstered by further research (Cohen et al. 2011, but see Wilson et al. 2008 for an alternative calculation)—they come to inform guidelines and policy.

**Descriptive Epidemiology**

For the majority of the years since the advent of AIDS, HIV-serodiscordant couples have been an unknown population. It is only relatively recently that data on HIV status have been collected from nationally-representative samples (in Africa see, for example, de Walque 2007, Eyawo et al. 2010). Obtaining a credible estimate, therefore, on how many people around the world live in serodiscordant unions is not yet possible. Nonetheless, scholarly attention to serodiscordance dates back decades. As previously mentioned, Nancy Padian headed a series of important, large, prospective studies on couples and HIV transmission (the California Partners studies) that began in the mid to late 1980s. This research produced an estimate of constant per-contact infectivity of HIV (0.0009 for male-to-female transmission), reported that condom use within the serodiscordant sample diminished over time, and documented the importance of STIs in seroconversion (Padian et al 1997:353-354). Other studies have also calculated infection rates. In Zambia, for example, these ranged from 2.3/100 couple-years (c-\(y\)) for couples who reported condom use at every intercourse, to 10.7/100 c-\(y\) for less consistent users (Hira et al. 1997:243). A year-long study in Pune, India reported HIV incidence among uninfected partners was 1.22 per 100 person-years (Mehendale et al. 2006). Powers et al. (2008) note that “one
transmission per 1000 sexual contacts” has become a commonly cited estimate of HIV infectivity. But, questioning whether study methods might have affected these estimates, they conducted a systematic review of the literature. They found divergent results, depending on the focus of particular studies, thus, they note that "A single value for the heterosexual infectivity of HIV-1 fails to reflect the variation associated with important cofactors. The commonly cited value of 0·001 was estimated among stable couples with low prevalences of high-risk cofactors, and represents a lower bound. Cofactor effects are important to include in epidemic models, policy considerations, and prevention messages" (Powers et al. 2008:553).

Other studies have focused more on measuring unprotected sexual contacts within serodiscordant couples. Van der Straten et al., for example, examined the sexual practices of couples in the California Partners cohort. They found that “over two-thirds of couple members surveyed reported unprotected sex with their partner in the past 6 months” (Van der Straten et al. 2000:F47; see also Buchacz et al. 2001). Kalichman and co-authors also found unprotected sex to occur between serodiscordant partners in the U.S. Specifically, they (Kalichman et al. 2002:678) noted that study participants:

with regular serodiscordant partners engaged in significantly greater unprotected and protected vaginal intercourse, greater rates of overall unprotected, condom protected, and total intercourse occasions than their counterparts with non-regular partners. Persons with regular partners also indicated using condoms significantly less in proportion to total intercourse occasions than persons with non-regular partners.

47 Indeed, they are not alone in this line of thinking. Kempf et al. (2008), in their article on enrollment of serodiscordant couples for the large cohort in Lusaka, Zambia, found that retention bias is significant. 48 Contrary to the fear sometimes expressed that HIV treatment will prompt seropositive people to engage in unprotected sex, however, treatment availability did not appear to explain this. Perceptions on the part of seronegative respondents that that their partner had an undetectable viral load were significantly associated with having protected sex, and “seropositive respondents taking protease inhibitors were 2.4 times less likely to report unprotected sex compared with those not taking protease inhibitors (P < 0.05)” (Van der Straten et al. 2000:F47).
Another study described sexual practices of HIV-positive Papua New Guineans on ARVs, stratifying by partner serostatus. While “a greater proportion of those in HIV-serodiscordant relationships [report] ‘always’ using condoms for sexual intercourse with their regular partner, compared to those in HIV-positive seroconcordant… or those who did not know their partner’s HIV status,” this trend did not reach statistical significance (Kelly et al. 2011:736). In general, then, this literature suggests it is unwise to assume that serodiscordant couples consistently practice safer sex (see also Crepaz and Marks 2002:146).

By 2000, however, awareness was spreading about the key role played by viral load in HIV transmission. One important site for this research was the population-based study in Rakai, rural Uganda. Ninger (2000:203) reports that among 415 serodiscordant couples, “The viral load of an HIV-positive sexual partner is the most important factor affecting heterosexual transmission of the virus... No seroconversions occurred when the HIV-positive partner's viral load was less than 1,500 copies per milliliter.” Melo et al. (2008:912) agree with this general assessment. In their study of 93 serodiscordant couples in Porto Alegre, Brazil, six seroconversions occurred; “In all cases index partners were not using ARVs at the time of seroconversion. Transmitters showed significantly higher median viral loads (P < 0.042) suggesting that heterosexual transmission of HIV is more a function of viral load than gender of index case.”

A relatively recent turn in basic demographic research on serodiscordant couples has been made possible by nationally-representative household surveys that include information about HIV serostatus. De Walque (2007) analyzes these data from Kenya, Burkina Faso, Tanzania, Ghana, and Cameroon, to report two main findings. First, of self-reported HIV-infected couples in these countries, at least two-thirds are serodiscordant, suggesting the
importance of prevention efforts for this population. Second, among 30-40 percent of the infected couples only the woman is infected. This, the author notes, calls into question “the common perception that unfaithful men are the main link between high-risk groups and the general population” (de Walque 2007:501). Eyawo et al. (2010:770) expand on this analysis. Based on data from multiple sources but including “27 cohorts of 13 061 couples and [Demographic Household Survey] data from 14 countries of 1145 couples,” the authors found that, in sub-Saharan Africa, women were as likely as men to be the index case in serodiscordant couples.

Reproduction

Another important topic covered in the literature is reproduction within serodiscordant couples. These publications come from bioethicists (e.g., Reame 2003, Savulescu 2003) as well as biomedical practitioners and social scientists. Opinions vary, but have also evolved along with advances in knowledge about HIV, especially the prevention of mother-to-child transmission and so-called “sperm washing” (Kuji et al. 2007). Thus, Bujan, Daudin, and Pasquier argued in 2002 that assisted reproduction was feasible for serodiscordant couples, but natural conception should be avoided. By 2006, however, Barreiro et al. had published evidence from 62 Spanish, serodiscordant couples that included no partner seroconversions and only one case of vertical transmission in 68 live births. They argued in a subsequent publication (Barreiro et al. 2007) that natural conception should be accepted as long as the seropositive partner had achieved complete viral suppression.

Given effectiveness of ARVs and the importance of childbearing in many cultures (see above for work on this topic in the Brazilian context; see also Richey 2011), desire on the part of serodiscordant couples to form families should not be surprising. Indeed, some specific attempts
to control conception among this population have proven futile. Mark and co-authors report on a three-armed, randomized controlled trial (RCT) of an intervention to promote dual method contraceptive use among couples (including serodiscordant couples) in Zambia. Although there was significantly better uptake in the test arms, no differences were found in incident pregnancy among the three groups thereafter (Mark et al. 2007:1200). A slightly different angle on the phenomenon of childbearing by serodiscordant parents is offered by Pereira et al. (2011), who report on cases encountered through their counseling work at a hospital in Portugal. Like Brazil, Portugal has made HIV testing part of routine pre-natal care; due to this initiative, many women only learn they are seropositive during what the authors call the “transition to motherhood.” This is said to constitute "a major life trauma for both members of the couple," with further transmission (be it sexual or vertical) characterized as “the main risks that couples face when considering reproduction and parenthood” (Pereira et al. 2011:143, 145). Although the authors briefly address “perceived or expected stigma and discrimination” (Pereira et al. 2011:151) related to serostatus, the article focuses on providing guidelines for sessions with couples as they initially find themselves in this situation.

**Explanations for Risk Behaviors**

Other studies concentrate specifically on documenting or explaining why serodiscordant couples persist in what is termed “risky” sexual behavior, frequently combining quantitative and qualitative methods. Guimarães, Boschi-Pinto, and Castilho (2001), for example, report on cross-sectional data collected between 1990 and 1994 in Rio de Janeiro. HIV-positive men and their female partners who had known of the male’s serostatus for at least four weeks were interviewed separately, to determine predictors of “safe sexual behaviour,” defined as "no unprotected vaginal, anal, or oral intercourse" (Guimarães et al. 2001:335). Statistically
significant predictors of this behavior included: age older than 30, (female) seronegativity at the
time of study participation, advanced clinical stage of husband’s infection, relationship duration
of 10 years or longer, fewer sex contacts, one lifetime partner (for the female), no oral sex, and
having had a previous HIV test. But even in this pre-HAART era cohort, unprotected sex was
reported by 131 of the 328 couples, including 51 who were serodiscordant at the time of
recruitment (Guimarães et al. 2001:339). Echoing findings from the California Partners study,
"women who had known their partner's infection for longer were less likely to report safe sexual
behavior (P < .001)” (Guimarães et al. 2001:334).

Although Guimarães and co-authors do not attempt to theorize the pathways by which
these factors come to have an effect, as noted in the above section on public health research,
other scholars have offered explanations derived from psychological frameworks, for example
distress (Skurnick et al. 1998), depression (Bradley, Remien and Dolezal 2008), or “sensation-
seeking” and negative beliefs about condoms (Israel et al. 2005). More recently, Ngure et al.
(2012) opted for a qualitative approach to understanding barriers to condom use among
serodiscordant couples in Kenya. The authors identified four principal barriers among couples
aware of their respective serostatuses, each of which fits in with findings already discussed in
this essay. First, male partners, regardless of serostatus, were reluctant to use condoms. This was
attributed to reduced (male) sexual pleasure, and alcohol use, with female partners reporting
suspicion that men even feigned drunkenness to avoid condom use. Second, female partners
were unable to insist on condom use, reporting that their requests “sometimes sparked anger that
led to verbal abuse, withholding of economic support, and in extreme cases, physical abuse”
findings, this study documented “misconceptions about serodiscordance,” including seronegative
men’s convictions of immunity to infection, couples believing that God would protect the negative partner from HIV, and some couples questioning the validity of their discordant serology, since they had previously not used condoms (Ngure et al. 2012:513). Finally, the desire for children was common, and awareness of assisted reproduction was not universal. Among couples who were aware of these techniques, some voiced a negative opinion (Ngure et al. 2012:514).

Despite the recent publication date of this article, the authors reported their initial assumption that serodiscordant couples cognizant of their respective serostatuses would be “highly motivated to adopt consistent condom use” (Ngure et al. 2012:510). In the presentation of their study, they claim that, “it now appears that this group also faces formidable challenges to consistent and correct condom use” (Ngure et al. 2012:510, emphasis added) and that not all people (particularly women) are able to act on their desire to prevent HIV transmission. It is as though they are unaware of the last 15 years of research with this population. Perhaps predictably, their recommendations include providing couples with more information, “to dispel misconceptions,” and training in “skills to negotiate safe condom use” (Ngure et al 2012:515). The presumption (frequently shared by reports on interventions designed to reduce “risk behaviors,” e.g., McGrath et al. 2007) is that it is the barriers identified by scholars that prevent serodiscordant couples from using condoms, and, therefore, removal of those barriers will result in less exposure to the virus. That is, couples’ desire to avoid transmission—their perception of the undesirability of HIV risk—is taken as axiomatic.

A meta-analytical approach to HIV risk is in serodiscordant couples taken by both Crepaz and Marks (2002) and Guthrie, de Bruyn, and Farquhar (2007). The former review encompassed 61 articles, 50 of which reported on research conducted in U.S., and was designed to calculate
“effect sizes indicating the magnitude of association between unprotected sex” (Crepaz and Marks 2002:136) and an extensive list of correlates derived from public health approaches to risk. The authors found support for concepts invoked by the Health Belief Model, the Theory of Reasoned Action, the Theory of Planned Behavior, and the AIDS Risk Reduction Model, Social Cognitive Theory, among others (Crepaz and Marks 2002:144). Guthrie et al.’s focus was different, both geographically and thematically. More of the studies they incorporated in their analysis came from sub-Saharan Africa than the rest of the world combined (2007:416), as is perhaps fitting, given the global distribution of HIV infection. These authors advocate the study of serodiscordant couples for the express purpose of “understanding correlates of HIV-1 immunity and acute infection” (Guthrie et al. 2007:416) more generally, as well as targeting prevention efforts. Based on their calculations, they provide an infectivity estimate of 1.2-19 per 100 person years; .9 to 1.2 per 1000 coital acts, identify “STIs, particularly genital ulcerative diseases, HIV-1 viral load, condom use, and specific sexual practices” as important correlates of transmission, and note that provision of HAART to the infected partner "may benefit both partners by reducing viral load in the genital compartment and reducing the risk of transmission" (Guthrie et al. 2007:417, 425). In addition to further research, their main recommendation involves increased premarital testing and counseling, particularly in mature epidemics (Guthrie et al. 2007:426).

The foregoing foci of research on serodiscordant heterosexual couples have produced important findings, particularly considering that some of these studies (e.g., Padian et al. 1997; Hira et al. 1997; Guimarães et al. 2001) were conducted prior to the era of HAART. Among the most important to keep in mind as data from this dissertation are presented are: 1) unprotected sex does not automatically lead to HIV transmission. The characteristics of the couples
participating in this research may in fact closely approximate those associated by Powers et al. (2008) with the “lower bound” of infectivity; 2) heterosexual serodiscordant couples must not be assumed to practice safer sex, and they may be least likely to engage in such behavior with stable/primary partners and in relationships of longer duration; 3) non-use of condoms is frequently attributed to male partner resistance, female inability to insist, and desire for children; 4) factors related to seroconversion of the HIV-negative partner include inconsistent condom use, but also other STIs and seropositive partner viral load (specifically, transmission is far less likely at < 1500 copies/mL); and 5) couples may not even find their status as serodiscordant credible, and may express other interpretations of their serology.

**Serodiscordance as Lived Experience**

What is largely invisible in the research reviewed above is the larger context in which “risk behaviors” occur, whether that entails a focus on serodiscordant couples *qua* couples, or on the members thereof as also participating in varied ways and roles in the wider society in which they live. Instead, serodiscordance is often either disregarded entirely (as when sexual behaviors that occur in a known situation of potential transmission are equated with sexual behaviors more generally), or implicitly treated as a totalizing identity (as when researchers position preventing HIV transmission within the couple as an unquestionable priority). This becomes apparent when one considers scholarly production that focuses on couples in general, rather than HIV-serodiscordant couples specifically. In dealing with couples whose HIV risk is theoretical, rather than resident in the body of one member of the dyad, many studies acknowledge that relationship context and the meaning of particular sexual acts can take precedence over HIV prevention (e.g., Bajos and Marquet 2000, Maia et al. 2008, Marqués et al. 2007, Stein et al. 2007). There seems to be much more room for multiplicity in studies of couples who are (or are assumed to be) HIV-
concordant and seronegative, whether regarding the multiple goals of health communication within couples (van der Straten et al 1998) or the multiple implications of condom use as an risk reduction strategy (Kraft et al. 2007).

In contrast to the scholarly work reviewed above, there is a growing body of literature that recognizes the particularity of serodiscordance, foregrounds meaning and emotion as relevant issues when considering relationships and sexual practices in serodiscodant couples, and even pauses to ask what serodiscordance means. Such intellectual moves can also, incidentally, entail revised approaches to the concept of risk. This continuum of critical awareness is structured, to some extent, by the socio-temporal divides mentioned earlier, and, presumably, the evolving experiences of the population under study. The kinds of questions asked by these researchers were likely far less relevant (and perhaps not even possible), for example, before combination therapy made it plausible to consider HIV a chronic disease, and the impact of this shift on serodiscordant couples’ lives was surely not immediate, but, rather, gradual, percolating through days and nights of hesitatnt hope to take on the substance of a future to be lived. As such, it is a relatively nascent field, developing over time (which is not to say that all the work considered here exercises radically critical reflexivity), but guided by the same simple question that animates this study: What is it like to live in an HIV-serodiscordant couple?

The Influence of Biomedicine

One of the earliest, frequently cited treatments of this topic that incorporates the world beyond the couples in the answer is a publication from the California Partners study. The data on which the article was based were actually gathered in an attempt assess the partner study format, however, the team discerned themes in the data that also spoke to other issues, namely: “1) the role of serostatus identity and stigma in shaping the couples’ experience of HIV; 2) the
responses to stigmatized sexuality, including strategies for negotiating sex and risk; and 3) the management of HIV in the private and public sphere” (van der Straten et al. 1998:4). Through interviews and focus groups, the 28 participants articulated that they sometimes felt alienated from their partner as a result of their different serostatuses, but that services and spaces reserved exclusively for HIV-positive individuals served to accentuate this (van der Straten et al. 1998:6). In addition, although it may appear contradictory, the serostatus distinction between members of couples was often blurred; “it was not uncommon to have participants refer to themselves as an 'HIV couple' or [to say] 'we have HIV’” (van der Straten et al. 1998:7). It was clear that both members had to “deal with” with HIV, whether in terms of disclosure, stigma, or a loss or reduction in sexual desire. These experiences were all framed by respondents as resulting from the couples’ emotional attachment as well as the social environment. Couples took various strategies in response to these challenges, from being open about their serostatus to keeping it a secret, and from abstinence, to use of condoms, gloves, and saran wrap, to unprotected sex (van der Straten et al. 1998:8-10).

Like the California Partners study team, Polejack and Costa (2002) recognized that advances in HIV treatment made it imperative to widen the field of view beyond seropositive people. Drawing from their counseling work in the Brazilian context, they note that the transformation of HIV/AIDS into a chronic disease brings with it “the possibility of deconstructing the idea of imminent death,” the implication for patients, family members, and health professionals alike being that the focus becomes “the correct/certain future …questions such as treatment, life goals, sexuality, affection, work, relationships, etc.” (Polejack and Costa 2002:134). They focus their discussion on couples they, citing previous scholarship, term “sero-different,” eschewing the term “serodiscordant” for its “incapacity to account for the relational
context, a joint project based on love and conjugal dynamics” (Polejack and Costa 2002:135).

This linguistic statement of openness to new possibilities is joined by the authors’ inclusion of Sherr’s point that identifying sero-different couples as a particular kind of couple at all is problematic, since “they don’t have common goals, they don’t self-identify or recognize themselves in that way. The only characteristic they have in common is that one of the partners is not infected with HIV” (Polejack and Costa 2002:136).

Despite these positions, and notwithstanding important observations about the experience of serodiscordance, there is a tendency to interpret couple’s statements primarily in terms of their connection to biomedical paradigms. For example, it is noted that an HIV/AIDS diagnosis tends to be “a vital, meaningful crisis” (Polejack and Costa 2002:134), but that sometimes the principal complaint of couples in counseling is not HIV infection, but betrayal (through the presumed or actual infidelity that produced infection). What this says about those couples’ conceptions of HIV, or why this is so in some couples but not others are questions never raised by the authors. HIV is presumed to uniformly mean betrayal and uncertainty, and to require a “space for conversation and dialog in the relationship” to deal with effectively (Polejack and Costa 2002:135). Silence and secrecy are seen as detrimental in general, and particularly within couples. When one seronegative partner states, “We decided to live like a normal couple, so we don’t talk about that,” this is interpreted as “a non-verbal contract of the denial of seropositivity” (Polejack and Costa 2002:137). It is not my interest here to refute or concur with the authors’ reading of this particular case, but it bears noting that alternative interpretations do not even appear as a possibility. Must it constitute “denial” for two people to “live like a normal couple” when they are HIV-serodiscordant? If so, might that not reveal more about the priority accorded the biomedical management of risk on the part of the researchers (to say nothing of the
pervasiveness of the stigma attached to the virus) than it necessarily does about the couple in question?

Along similar lines, when van der Straten et al. (1998:9) report some participants’ beliefs that they are immune to HIV, this is termed a “purely psychological rationalization.” As in the previous example, this characterization might appear to be grounded in science, particularly as both implicitly reference biomedical notions of infectiousness. However, the assumption that a mechanism conferring immunity to HIV could not exist, simply because one had not yet been discovered, is not scientifically defensible (science, after all, is an exercise in disciplined uncertainty). Yet that is precisely the assumption behind such wholesale dismissal of participants’ explanations for non-transmission in a context of repeated exposure. Scientifically speaking, while a statement regarding the lack of evidence to support such conclusions would have been warranted, rejecting immunity as a possibility is, technically, just as unjustifiable as claiming it as causal—both statements extrapolate available evidence. Hence, again, it is not science but the priority accorded the biomedical management of “risk” that motivates such framings. Indeed, when risk is discussed in either publication, it is in terms of epidemiological evidence, viral load, stage of infection, etc. That is, only biomedical notions of risk are entertained.

Much the same can be said for any approach to serodiscordance that refuses to see certain ideas or statements as anything but “denial,” “rationalizations,” “misconceptions,” or “wishful thinking” on the part of the couple. This adherence to biomedical ideology forecloses certain analytical possibilities, and that limitation often goes unrecognized. This is not to say that important contributions to our knowledge are not made, merely that, if there is a persistent similarity in the ways serodiscordant couples are seen to be in denial or misinformed, it might be,
in part, produced by having evaluated their experience through the lens of biomedicine itself. As such, I limit further inclusions to this section to two contextually-relevant considerations.

Both Reis and Gir (2009) and Miranda et al. (2013) conducted qualitative research on serodiscordance in Brazil.\textsuperscript{49} The objectives of these studies were to “describe and analyze the vulnerability and prevention of sexual transmission of HIV between serodiscordant partners” (Reis and Gir 2009:663) in the state of São Paulo, and “to describe the living of seropositivity for HIV, from the social context to the sero-discordant conjugality”\textsuperscript{50} (Miranda et al. 2013:589) in the state of Goiás. Although carried out several years apart, with small samples (11 and 10 individuals, respectively), in different regions of the country (Southeast and Center-West), there are marked similarities in their findings. An overview is given of both studies; where their data overlap, they are discussed jointly.

From their data, Reis and Gir identify three main themes which may be translated as 1) naturalization, 2) relationship duration, and 3) non-transmissibility beliefs. The authors understand these as factors that contribute to the “vulnerability,” of the couple, following Ayres et al.’s (2003, 2006) three-pronged theorization of the concept mentioned above. The themes are so interrelated that it is frequently difficult to ascertain which one (or more than one) a segment of participants’ reported speech is intended to illustrate. The overarching story, however, is clear. Some interviewees have come to think of HIV infection as something “natural” (perhaps even “banal,” as Knauth et al. 1998 suggested), which diminishes the likelihood of consistent preventive practices. As one participant said, “He says that it’s not just AIDS that kills, he says diabetes kills more than AIDS does. We should take care anyway, but he doesn’t care; he says

\textsuperscript{49} For a remarkably similar picture of women’s experiences in serodiscordant couples in a U.S. context, see Stevens and Galvao 2007.
\textsuperscript{50} Note: This is what was published, although it is clearly a less-than-idiomatic translation of an article originally written in Portuguese.
that if he gets it, he gets it!” This attitude, however, was not limited to couples not practicing safer sex: “I don’t let it get to me, I live my life normally. I don’t think he runs any risk because we take very good care [i.e., the couple practices prevention consistently]” (Reis and Gir 2009:665). Particularly as time goes on, the absence of infection in the seronegative partner, despite multiple exposures, (further) reduces concern over this possibility. This is frequently interpreted as evidence of the non-transmissibility of HIV, a belief explained in various ways, among them use of condoms, undetectable levels of virus in the seropositive partner’s blood, and protection from God (Reis and Gir 2009:665-667).

Miranda et al.’s interest in serodiscordance was a bit broader, encompassing experiences of diagnosis and disclosure in addition to sexual matters. Their findings echoed Polejack and Costa’s, in that diagnosis was usually a traumatic event. In one participant’s words: “For me, it was terrible […] For me, it was a bomb, as if a bomb would fall upon my head” (Miranda et al. 2013:591). In addition, most interviewees reported experiencing and fearing stigma related to their serostatus. In general, the authors characterize their results as “concurring with other studies” that serodiscordance “is substantially permeated by fear.”51 They identify, among the many reasons for this fear, discrimination, losing one’s partner, transmitting HIV, being rejected, and “finiteness of life” (Miranda et al. 2013:595). On the other hand, they report that the majority of respondents characterize their intimate relationships as “quiet and normal” and sexually satisfying. A female interviewee said, “Now it is nice […] it is a normal living […] we date, go out, we walk together.” A male interviewee focused more on sex when asked about his relationship with his partner, noting “You need to have sexual intercourse […] because you do not live [if you don’t…] you miss it, I’m a normal human being” (Miranda et al. 2012:592).

51 Although not cited by Miranda et al., Amorim and Szapiro make a similar argument in their 2008 article on serodiscordant couples in Rio de Janeiro.
Although the authors do not address this seeming contradiction, one may assume that the fear produced by the situation of serodiscordance exists in tension with participants’ evident desire (again, echoing Polejack and Costa’s findings) for or experience of “normality.”

Although Reis and Gir emphasize the naturalization of HIV, while Miranda and co-authors focus on fear, their findings resonate on four issues: male resistance to condom use, prevalence of ideas of non-transmissibility or immunity to HIV, the importance of childbearing, and participants’ invocation of God. Notably, these data largely bolster the trends reported in work on AIDS in Brazil reviewed in a previous section of this chapter.

Reis and Gir do not specify the proportion of interviewees that report not consistently practicing safer sex. They do note that “many couples” opt to forego condom use as a prova de amor, or “proof of love,” and not out of ignorance of transmission routes (Reis and Gir 2009:665). Overall, the three major barriers to condom use were: lack of confidence in effectiveness, reduction in sexual satisfaction, and the attempt to strengthen the couple’s union. Miranda et al. report only that “the majority” of their sample asserts consistent condom use. Maksud (2007, 2009), however, presents data from a sample of Brazilian serodiscordant couples that suggest the male partner—regardless of serostatus—was almost invariably the decision-maker on condom use. In light of this, and the extended exploration of gendered meanings attached to condom use outlined earlier in this chapter, one wishes for more careful attention to gender in these later studies. For example, it should not be ignored that both of the illustrative quotes on condom non-use offered by Miranda et al. (2013:593) come from female speakers, and clearly construct men’s wishes as decisive.\footnote{The quotes are as follows: “We started using condoms, then we give it away, now I’m pregnant [...] then, he speaks: I do not like using condom, I like to do without a condom...” and “He does not allow having a sexual relation with a condom, he does not like and he does not have that kind of prejudice” (Miranda et al. (2013:593).}
This same gender blindness characterizes these studies’ treatment of beliefs regarding non-transmissibility. Miranda et al. (2013:592) assert that the extended survival time achieved through HAART “can lead the [seronegative] partner to have a false illusion of immunity to HIV, leading the couple to the inconsistency in condom use.” Likewise, Reis and Gir portray seronegative partners as “denying the possibility of infection with HIV.” Yet, again, the three quotes offered to justify this statement are exclusively from seropositive women. To give just one example: “I think that I’m the only one who perceives the risk, because he’s at ease about it, he’s calmer than I am. This kills me, I’m just dying of fear inside, it’s like I told him, I don’t want what happened to me to happen to anyone else” (Reis and Gir 2009:665). There is, clearly, an important difference to be explained here. And it may well be, as the authors suggest, that a seronegative partner who has witnessed the incredible impact of HIV treatment has come to view the virus as something “natural,” not worth “dying of fear.” On the other hand, it’s possible that a man and a woman, through a dismissal of risk and an exercise of caretaking, respectively, are convincingly performing socially important identities that have little (if anything) to do with serostatus. It is impossible, given the evidence provided, to tell. While one might speculate as to whether the same assumptions would be made were these couples not known to be serodiscordant, the lack of discussion about whether to view these interactions through the lens of serostatus or gender suggests that the priority accorded biomedical, risk-related explanations was not a critically-informed choice.

Yet another example of this dynamic has to do with reproduction in serodiscordant couples. The authors of both articles note the importance of childbearing in Brazil, and, ultimately, both pieces may be read as only very cautiously supportive of this possibility. Reis and Gir (2009:665) argue that, in their interactions with serodiscordant couples, clinic personnel
must emphasize the possibility of vertical transmission and limitations in care for the baby (presumably this is a reference to the prohibition of breastfeeding). According to Miranda et al. (2013:593), “most participants” worry about having children, whether that concern centers on potential transmission to one’s partner or the baby, health complications provoked by gestation, or the seropositive partner not surviving to see the child to adulthood. Some, though, consider it entirely feasible to conceive naturally; one woman is reported as saying, I don’t see anything wrong with that\textsuperscript{53} “[...] for me it’s normal.” Interestingly, this assertion of “normality” is actually constructed as not the norm among the sample. In addition, since childbearing is considered a “natural” function and, indeed, a right of Brazilian couples, for its “acceptability” to even enter into debate reveals just how fundamentally “different” these couples are seen to be.

Finally, religion, while cited as an important coping mechanism in terms of dealing with an HIV diagnosis, is also discussed by Miranda and coauthors (2013:592, 595) as “a negative influence, since it emerges with a potential to induce the individual to the false sense of protection, with impossibility of virus transmission.” Reis and Gir concur, noting the role of religion in beliefs about non-transmission. They offer the case of one male participant who had been involved with two different seronegative women, neither of whom seroconverted. He asserted, “I have to praise God; neither of them has it...I am not a transmitter” (Reis and Gir 2009:666). This statement, and all others like it, is interpreted as unfortunate, a misconception, an impediment to HIV prevention. What is never considered is its literal truth. If neither of this man’s sexual partners contracted HIV, then his words, “Eu não sou transmissor,” are a statement of fact, whatever else they may be.

And, on the most fundamental level, if the object of study is serodiscordant couples’ own understandings of their lives, determining the veracity of this man’s words is immaterial.

\textsuperscript{53} This is an idiomatic paraphrase of the quote offered in the article.
Whether or not they correspond to a scientifically verifiable reality, they are a doorway to his worldview, to the way he lives his seropositivity. But here again we are brought up short, and analytical possibilities are foreclosed, by the insidious (because unacknowledged) influence of biomedical notions of risk and serodiscordance. While this might be expected in other types of studies (e.g., see above for discussion of Bunnell et al. 2005; also Porter et al. 2004), the persistence of this orientation in work that purports to take the perspectives and experiences of these couples seriously is striking. It should, however, be interpreted less as an analytical failure, and more as an indication of just how deeply entrenched biomedical approaches to risk and serodiscordance are. Although much more could be said about all of the research reviewed here, I believe the basic point has been adequately made. Far more interesting and productive is the introduction of scholarship on serodiscordance that strikes out in new directions.

The Meanings of Serodiscordance: Contingent and Multiple

While it is true that no academic writes alone (even Gramsci, for example, in his Prison Notebooks (1971), is in dialogue with other scholars), it is also true that the work of one individual occasionally pulls together disparate threads from various sources and, through their own, delicate, intellectual weaving, produces something qualitatively different than what came before. This is what Asha Persson has done for the literature on HIV-serodiscordant couples. Beginning in 2008, in a series of publications based on data from the Straightpoz study, a “qualitative, longitudinal cohort study of HIV-positive men and women and HIV-negative partners” in New South Wales, Australia (Persson 2008:503), she and her co-authors have gained increasing and definitive critical distance from the hegemony of biomedical notions of serodiscordance and risk. Some of the most important conceptual innovations from her work include: the notions of sero-sharing and sero-silence (Persson 2008), and proxy negativity.
(Persson and Richards 2008), as well as complex examinations of the contingency and multiplicity of “serodiscordance” and especially the status of seronegativity within serodiscordant couples (Persson and Richards 2008; Persson 2011; Persson 2012b), as well as the corporeality of HIV (Persson 2012a). Although other researchers are beginning to apply these ideas in their own work (e.g., Rispel et al. 2012), this review is limited to Persson’s publications, which promise to mark a seminal moment in the serodiscordance literature.

Straightpoz is a multi-phase study that began in 2004. In-depth, semi-structured interviews and some fieldwork were conducted with 46 total participants, who belonged to 19 serodiscordant couples. In almost half of these couples (N=8), both partners participated, while in the rest (N=11; six HIV-positive and 5 HIV-negative) only one member did. In eight of the 19 couples, the female is the seropositive member (Persson 2008:503-504). Persson notes, as also highlighted previously in this essay, that most literature on serodiscordance assumes healthy management of HIV is only possible with open, frequent communication between partners. She questions this assumption, however, particularly in light of what she argues are the two main modes the couples in her sample employ to deal with their serostatus: sero-sharing and sero-silence.

In sero-sharing, “both partners engaged in the emotional and practical management of HIV;” however, this was “not necessarily defined by communication, but rather by the acknowledgement of HIV as a formative presence in the relationship” (Persson 2008:504). In addition, as reported previously by van der Straten et al. (1998), there was also frequently a shared identity as an “HIV couple.” In contrast, “sero-silent mode, HIV was very much in the background and was seen by either or both partners as the domain of the positive partner, rather than as a shared experience” (Persson 2008:504). Aside from the catchy names, the literature on
serodiscordance in replete with similar findings. What sets Perssson’s approach apart is her interpretation of these behaviors. In the first place, she refuses to issue an unequivocal pronouncement on the value of these strategies. Secondly, she sees as overly simplistic any mutually-dichotomous division between sharing and silence, as well as the attribution of a totalizing characterization to individual couples’ practice. She explains that these strategies are “not understood as functional or dysfunctional…[and] all relationships had overlapping and complex shades of both” (Persson 2008:504). She urges more nuanced analysis of both how particular incidents of sharing or silence fit in the context of the relationship, as well as the specific way those strategies are deployed, arguing for consideration of both modes as “a potential medium of both support and denial, as both a skilled and unskilled practice and as having both positive and troubling effects on couples’ health, happiness and sexual decisions” (2008:506).

As demanding an analytics as this entails, Persson does not view it as complex enough to encompass the social phenomenon of serodiscordance. Another factor that must be accounted for is how gender plays into and differentially constructs serostatus within serodiscordant couples. She and Richards (2008:801) consider this dynamic, based on a slightly reduced cohort from the Straightpoz study: 16 participants, from 11 couples. Both partners in five couples participated, although the interviews were conducted individually. Four of the couples who were not sexually active figure somewhat less prominently in the data. By focusing on HIV-negative female partners, two phenomena came into view. This first was the destabilization, indeed, the contingency of serostatus. The second, following from the first, was termed “proxy negativity” by the authors. The argument merits consideration at some length.
The first important observation in the paper is the way studies influenced by biomedical models of serodiscordance customarily aggregate individuals by serostatus, thereby erasing the differences within groups. Specifically, reference to “HIV-seronegative women” (or any gender, for that matter), glosses over any “distinction between those who have no contact with HIV in their daily lives and those who do….For women in sexual relationships with HIV-positive men, HIV-negativity is not experienced reductively as simply an absence of HIV evidenced by a medical test; it is defined by, and does not exist outside of, their intimate relationship with their HIV-positive partner” (Persson and Richards 2008:801). In addition, because of the so-called “window period” in HIV testing (the lag between infection and the body’s production of sufficient antibodies to produce a positive result), in a context of repeated exposure, HIV-negativity is never definitive; it is always merely the measurement of a past condition. It is, therefore, “a serostatus that is lived in the immediacy of HIV, not in its absence” (Persson and Richards 2008:801). This ambiguity is taken further subsequently, with Persson (2011:570) describing HIV-negativity as a liminal state. Before addressing the rest of the authors’ argument, though, gendered aspects of the particular serostatus configuration being discussed must be mentioned.

To fully appreciate the analysis developed by the authors, it is important to know that HIV/AIDS in Australia remains strongly identified with gay men. Therefore, in a context of patriarchal heteronormativity (in which the privilege attached to masculinity and heterosexuality, following feminist intersectional theory, cannot be understood in isolation), an HIV diagnosis not only calls into question a man’s sexual orientation/practice, but his masculinity, as “it also compromised their ability to father children and, frequently, their physical ability to work and ‘provide’” (Persson and Richards 2008:802). Stories from men in this sample, however,
portrayed relationships with HIV-seronegative women as having the power to erase this mark of the Other. As Persson and Richards (2008:803) elaborate:

Becoming part of a serodiscordant relationship introduced a quantum of true HIV-negativity into the men’s lives, which diluted the perceived intensity and shame of their HIV-positivity…. The mixing of serostatuses made it possible for the men to assume a kind of proxy negativity, a desired state of redeemed masculinity in the absence of an even more desired cure for HIV.

The type of “transmission” going on within these couples has not previously been discussed in any of the serodiscordance literature. Rather than focus on the virus, Persson and Richards see the overwhelming importance of other kinds of social identities, and the way serostatus can be used as a vehicle to further those performances and projects. This analysis is made possible by their recognition of the indeterminacy of serostatus as it is experienced by serodiscordant couples, and by the refusal to automatically classify such conceptions as “denial” or “rationalization.”

Taking proxy negativity seriously also enabled the authors to attend to its internal differentiation, and discern ways those differences could help explain sexual practice within serodiscordant couples. One version of proxy negativity, termed “Protecting the Difference,” was frequently associated with safer sex: “women’s HIV-negativity and its normalizing power were safeguarded by carefully maintaining the physical boundary between the two serostatuses through the use of condoms” (Persson and Richards 2008:804). The other iteration, “Erasing the Difference,” involved a “‘disappearing’ of his HIV-positive status into her HIV-negativity and its reassuring heteronormacy. This blurring effectively removed any rationale for practicing protected sex” (Persson and Richards 2008:805). As an example of this latter dynamic, the reader is introduced to Mahmoud and Lowanna. The couple, who, after three years together had just had a child, eschewed condom use. They stressed that “HIV was ‘not an issue’ for them,
that they wanted to live a ‘normal life’; a life not dominated by HIV” (Persson and Richards 2008:805). This is in part because, as Mahmoud said, due to his adherence to HAART, “I don’t think I can [transmit HIV]…There’s not enough in my blood” (Persson and Richards 2008:803).

As the authors again resist playing the “denial” card in response to this couple’s statements and choices, we learn still more about less obvious ways HIV risk can be structured by gender. Although one might expect, given findings from the literature on male resistance to condom use, that the decision to engage in unprotected intercourse was Mahmoud’s, Lowanna claims it as her own. In addition to what may be seen as the “naturalization” (in Reis and Gir’s terms) of HIV, the priority accorded emotional intimacy with the relationship, and the salience of viral load, however, a further input to this choice becomes apparent, increasing its already prodigious complexity. Lowanna explained when Mahmoud was forced to confront his serostatus, he became depressed, edgy, controlling. Thus, it benefitted both members of the couple when he did not think about HIV. She conceded that unprotected sex might be a way she subconsciously worked to make that possible. Persson and Richards (2008:805) state:

Thus, Lowanna’s efforts to protect Mahmoud from his vulnerability to HIV, and herself from its effects, hinged on her making herself vulnerable in a highly gendered way. As such, her story clearly reveals how gender dynamics can play out in subtle and complex ways around serostatus not easily captured by the prevailing vulnerability discourse.

In a further exploration of HIV-negativity as an identity, Persson rejects the tendency of other scholarly treatments to view seronegative members of serodiscordant couples primarily in terms of their ability and willingness to negotiate or minimize the risk of seroconversion. Instead, she argues that “HIV-negativity takes on multiple and localized shapes as it is brought into being by different practices and contexts” (Persson 2011:570) and that it may not be a salient or solid enough consideration on which to construct a conception of the self. Based on data gathered
through interviews, even seronegative individuals in serodiscordant relationships were frequently at a loss to explain what their serostatus meant. As the author (Persson 2011:580) explains:

"One explanation is the general absence in the heterosexual community of any cultural dialogue around HIV, let alone what it means to be HIV-negative and yet have HIV in one’s life. It is an experience with no shared language and little social recognition as a particular kind of serostatus. Another explanation is that, for some, HIV simply had little impact on their lives or identity, either because their partner had always been well or because they had invested heavily in a sense of ‘normality’ as a way to manage and minimize HIV. A third explanation is the partners’ close proximity to HIV; their serostatus was inextricably bound up with HIV positivity by virtue of their serodiscordant relationship.

What is clear is the fraught relationship between HIV-negativity or serodiscordance more generally, and ‘normality.’ The theme of being normal, or doing things normally, has found intermittent expression throughout the scholarly work on serodiscordance reviewed here, although it is not usually examined in much detail by the researcher. It surfaced, for example, in the words of a participant in Polejack and Costa’s (2002) study, who claimed HIV/AIDS did not figure in the couple’s conversations very frequently (and also, potentially, that it did not exercise any influence on their sexual practice). Reis and Gir (2009) also offer the speech of their participants to illustrate how naturalized the virus has become, and how little importance is consequently assigned to prevention. The paper by Miranda et al. (2013) is peppered with participants’ references to what is considered ‘normal,’ whether in terms of childbearing, the quality of participants’ relationships with partners, or men’s need for sex. Lest we conclude that it is only in Brazil that serodiscordant couples are concerned with such issues, however, it should be observed that ‘normal’ has also appeared in speech reported from serodiscordant couples in Papua New Guinea (Kelly et al. 2011), Uganda (Bunnell et al. 2005), and Australia (Persson 2008, 2011) as well. In most of these usages, ‘normal’ is a condition research participants
(strive to) embody, and this effort or achievement is usually positioned as implicitly despite infection with HIV, or in juxtaposition to demands imposed by the virus.

Attempts by couples like Mahmoud and Lowanna (above), to have a “normal” life fall within these same general parameters. Persson, unlike other researchers, however, asks why normality should be so assiduously pursued, and is therefore able to demonstrate that far more than possible seroconversion is at stake in practices like unprotected sex. Another prescription of biomedicine that gets tangled up in a comparable dynamic, and thereby imbued with specific, relationally-produced meanings, is HIV testing. As Persson (2011:585) explains, particularly for couples who employed the “erasing the difference” version of proxy negativity:

The act of testing had the capacity to disrupt heteronormality by bringing HIV into focus and raising the stigmatizing specter of infectivity. This…explains why HIV-positive partners sometimes felt ambivalent about testing and why a few were quite comforted by, and even romanticized, their HIV-negative partner’s seeming disinterest in testing.

The further consideration of “normality” in Persson’s more recent work gains another dimension. Whereas most mentions of this concept by participants in other studies are relatively straightforward associations of “normal” with “not infected,” some interviewees in the Straightpoz study report more ambiguous understandings. One 40-year-old, female, seronegative participant, for example, described herself “as normal, and yet not: ‘I’m normal. . . . To be negative means that I have a normal life. To be in a positive–negative relationship is not normal, and that I find a bit, um, challenging I suppose’” (Persson 2011:580). This leads the author to note that, although being HIV-negative in Australia (and, I would argue, in the U. S. and Brazil as well) is an “unmarked category” and, hence, “normal” (Persson 2011:576)54, seronegative members of serodiscordant couples seem not quite to fit this description. Their serostatus is not positive, but not definitively negative—it is liminal.

54 For another examination of “unmarked” categories, see Frankenberg 2010.
Another transitional status that Persson’s work explores is that of the infectious corporeality associated with HIV. That Straightpoz was a longitudinal, multiphase study allowed the documentation of change over time within the serodiscordant cohort it followed. Quasi-experimental conditions were therefore created by the publication of the Swiss Consensus Statement (Vernazza et al. 2008) which, as previously noted, suggested that under certain conditions, HIV-positive individuals on stable and effective treatment might forgo condom use with their monogamous sexual partners. Follow-up with the cohort in 2009 did not produce evidence that serodiscordant couples were generally aware of the Statement, let alone embracing its message (Persson 2010). Ultimately, these findings led Persson (2012:1-2) to ask, “whether a body that has been feared as one of the most dangerous, contagious and abominable bodies in history can be decisively reimagined and reinhabited as non-infectious and harmless. Is it possible that, through technoscientific intervention, such a body could make a transition to something resembling ‘normality’?”

The answer, of course, is far from simple, and we need not go into the details here. In general, assessments of infectiousness were not only predicated on biomedical knowledge, and were not necessarily stable over time or in varying contexts. Instead, Persson (2012a:8) views seropositive corporeality as “a set of tensions,” produced by and existing “between conflicting discourses of infectiousness.” All of this analysis is brought to bear on a more general consideration of serodiscordance and risk, published in 2012, in which, much as has been done in this review, other studies of serodiscordance are analyzed, their contributions to our knowledge lauded, and their limitations pointed out. As I hope I have made clear, and as Persson (2012b:3-4) has stated much more eloquently, “At issue in this critique is not whether technicoscientific assessments of risk are true or not. Rather, it is the way differences between expert and lay
perspectives become reduced to an effect of erroneous thinking on the part of lay people, when in reality many and varied factors might be at play, bringing competing logics and contingencies to bear in the ways people assess risk.” She urges other scholars to “examine what HIV ‘risk’ actually means in different cultures and contexts” and to take a “‘socially situated’ approach to HIV risk moves beyond its scientific conceptualization as an objective ‘fact’” (Persson 2012b:1-2)—an exhortation to which this research was, unbeknownst to me at the time, already responding.

**Conclusion: A New Frontier of Risk**

As can be seen from the foregoing review, scholars have approached sex-related risk for HIV in various ways, ways that are often of a theoretical piece with their conceptions of sociocultural reality. Work in public health and medicine provided an early foundation that initially embraced “risk groups” and then attempted to move toward a more scientific, if somewhat individualist, conception of “risk behavior.” It rapidly became clear, however, that providing information about modes of transmission and ways to avoid exposure was insufficient to stop the spread of HIV. Social scientists of all stripes undertook to increase the effectiveness of prevention efforts by identifying barriers to their uptake—whether economic, cultural, or logistical. Incorporating theoretical constructs, such as social support, self-efficacy, and cultural appropriateness, occurred alongside quantitative approaches to identifying risk factors, particularly in epidemiology. While these efforts are sometimes parodied as “circle the significant result,” most scholars who work on topics related to HIV/AIDS rely on the results quantitative methods produce. In addition, in the public health literature it is increasingly easy to find sophisticated efforts to synthesize quantitative methods and social theory, as well as qualitative studies that make deeply theoretical arguments linking findings to epidemiological
data. In particular, analytical attention to gender and power (Zierler and Krieger 1997; Wingood and DiClemente 2000), and social inequalities more generally (e.g., “vulnerability:” Ayres et al. 2003, 2006; “syndemics:” Brennan et al. 2012; Kurtz et al. 2012; Talman et al. 2013) has widened the scope of factors to consider when thinking about risk in public health.

In that the research reported in this dissertation never disregards established, scientific knowledge about HIV, and, in fact, was partially brought into existence as a response to documented epidemiological trends in Porto Alegre, it might well be said that the approach to risk taken here falls into the category of critical realism (Carter and New 2004). Although often backgrounded in the analysis, considerations of infectiousness (as measured by CD4 counts and viral load), modes of transmission, and the imperfect but nevertheless impressive effectiveness of barrier methods and HAART are always present, and profoundly influenced the data I thought it relevant to collect.

I have used the idealist-materialist debate (Irvine 1989:248) as a lens through which to refract the strengths and weaknesses of anthropological efforts to conceptualize HIV risk. It is evident that the tendency to see oft-naturalized domains of social life, like sexuality, as constructions has been key to anthropological contributions to understanding HIV risk. The attention accorded to meaning, intimate relationships, and power in such analyses is critical to this research, as it serves to illuminate the contours and interconnections of gender, sexuality (both in terms of a cultural domain and as particular sexual practices), and reproduction in Brazil. Specifically, the construction of masculinity as free and sexual (irrepressible desires enacted with multiple partners), as well as strong, both emotionally and physically (stoic and risk-dismissing; capable of procreating and providing for families), is a powerful inducement to behavior that exposes men to HIV. Likewise, hegemonic conceptions of femininity (including
sexual desire and experience that are comparatively less than that attributed to men, the primacy of caretaking and motherhood, and subjection to men in general—particularly their sexual inclinations) within a patriarchal and heteronormative society incentivize gendered performances that are likely to bring women into contact with the virus. Idealist conceptions of risk, however, may neglect to inquire after the origin and mechanics of power and discourse. They may also give short shrift to the material and temporal structures within which social relationships and cultural ideals are developed and maintained. Appropriate care must be taken to interrogate these factors.

Materialist conceptions of risk, on the other hand, frequently address the importance of political economy and the historical trajectory behind the status quo—that is, their forte is precisely the focus on forces orders of magnitude larger than the individual. This orientation leads to attention, in this research, to various factors. It is not only the economic situation and prevalence of HIV in the social networks and neighborhoods of each individual serodiscordant couple that matters, but also the history of AIDS in Brazil, as well as the materiality of the government’s contemporary response. Neither poverty nor the presence of ARVs in the research context can be ignored. Rectification of idealist shortcomings, however, can come at the cost of appearing dismissive of individual agency. Assertions like Farmer’s (2004:307), that “the degree to which agency is constrained is correlated inversely, if not always neatly, with the ability to resist marginalization and other forms of oppression,” are seen as tautological, and do not satisfy critics. Weaknesses notwithstanding, both kinds of formulations illuminate the diversity of contexts that structure sex-related HIV risk, constituting a necessary addition to the quantitative focus that is still dominant in many epidemiological models.
The anthropological work considered in this paper that attempts to integrate materialist and idealist approaches often incorporates and historicizes international flows of people, capital, ideas, and power that constitute globalization while maintaining a focus on context-specific practices and processes of meaning production. In these treatments, the body is frequently the site in which material factors and ideational forces meet and mix (see also Van Wolputte 2004). As Susan Craddock has said, “Risk, as the prologue to disease, must at all costs be seen as historically situated, structured by institutions, households, and nations, and shaped by an ever shifting and relentlessly demanding global economy. But it must also be recognized that these structures and economies mesh inextricably with the social ideologies and cultural codes of particular times and places” (2000:164). These attempts to render a more complete picture of HIV risk might be criticized for their conceptual messiness. Were they rendered pictorially, multiple, interconnected, and nested feedback loops would fill the page; these schemas may be seen, in essence, as “turtles all the way down” (Geertz 1973). And yet by obviating attempts to pin down a single, necessary precursor to HIV risk, they have allowed us to turn our attention to new questions.

Until recently, anthropologists have generally taken for granted that, if people do not act to reduce their risk of HIV infection, it must indicate the presence of barriers. These include ignorance of, failure to perceive, and denial of risk, and facing insurmountable constraints to risk reduction. Only rarely questioned is the notion that risk is undesirable. Truly critical and holistic considerations, however, allow us to problematize the very nature of risk, and understand embodiment as a technology of risk negotiation—not an a priori attempt at reduction. As aptly demonstrated by the relatively few publications that consider the commodification of HIV,

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55 As previously mentioned, the social epidemiological studies I praise do not situate their study context this way, although issues of power, practices, and production are present.
seroconversion can be a celebrated event. Of special relevance to this research is the finding that, in a context of poverty, living conditions may improve subsequent to an HIV diagnosis—that is, when people have little to lose, the ability to “trade on serostatus,” even for relatively modest gains, may render typical understandings of “risk” nonsensical.

Finally, we may see this trajectory of conceptual refinement of risk as unfolding all over again within the literature on HIV-serodiscordant couples. Many of the same assumptions and shortcomings (that the prevention of infection is an unquestionable priority; that the context of exposure is irrelevant; that understandings of risk which diverge from biomedical wisdom are simply and unhelpfully wrong) took longer to overcome when applied to a situation in which risk was not hypothetical, but was embodied by one’s partner. However, new and deeply contextualized considerations of practice and subjectivity within serodiscordant couples have shown that little can be safely taken for granted. The most basic and revolutionary findings suggest that serodiscordance, far from being a unitary condition, defined simply by the results of serological tests, is multiple, contingent, and evolving; there is no single “necessary” understanding of risk that flows from such a phenomenon.

What is needed, and what I attempt to carry forward from this survey of the literature, is an approach to risk within serodiscordant couples that accounts for power dynamics as it traces the gendered, relational, economic, historical specificities of each dyad—in short, the ideal and material world they inhabit—and discerns how those influences come to fruition in their lived experience.
CHAPTER 4: METHODS

Research Objectives

The primary objective of this research is to develop a holistic understanding of how risk, especially the risk of HIV transmission, is constructed and negotiated in the daily lives of a group of heterosexual, HIV-serodiscordant couples in Porto Alegre, Brazil. This goal was formulated in response to the documented epidemiological importance of heterosexual transmission in the HIV/AIDS epidemic in the city, as well as perceived gaps in the academic literature on serodiscordance and risk.

Couples are admittedly a special case where HIV transmission is concerned, since not all sexual contact occurs within couples, regardless of whether that contact is heterosexual or same-sex. However, research has shown that HIV prevention (as indexed by condom use) is actually less frequent within established couples than with “non-regular” or “casual” partners (Kalichman et al. 2002; Hearst et al. 1999), which creates opportunities for transmission of the virus. Therefore, couples-based HIV prevention research is important if incidence of HIV is to be reduced. Serodiscordant couples cognizant of their serostatus have been noted as an ideal target population for such research precisely because they contain an infected and a susceptible individual who, in a known situation of risk, repeatedly deal with these issues (Guthrie, de Bruyn and Farquhar 2007:425).

However, this observation brings us to the second motivating factor for this project—gaps in the literature. There are three principal lacunae left by studies of serodiscordance and risk. First, as the preceding review (see Chapter 3) has made clear, in many studies of
serodiscordance, including the qualitative studies conducted in Brazil (Amorim and Szapiro 2008; Miranda et al. 2013; Polejack and Costa 2002; Reis and Gir 2009; but see Maksud 2009 as an exception), data are collected from the HIV-positive patient, not the couple. And yet, serodiscordance is a trait that comes into existence exclusively as a product of a relationship. Second, data for these studies were collected in therapeutic or institutional environments, often in HIV clinics and testing centers, raising the possibility that the location of data collection influenced participants’ responses. Collecting data in more neutral locations is challenging, in terms of time and accessibility, but must be done. Finally, and perhaps most importantly, these studies conceptualize “risk” as inherently undesirable, meaningfully quantitative, and infection-centric (but see Persson 2008, 2011, 2012b; Persson and Richards 2008 for a different perspective).

This study seeks to address the identified lacunae in part by recognizing that what we see is often a product of how we look. In this sense, the dearth of qualitative, and especially ethnographic, studies of serodiscordance and risk is especially noteworthy. According to Cresswell (1998:15-17), qualitative research often explores a human problem in a naturalistic setting by building a “complex, holistic picture,” highlighting participants’ perspectives and meanings. Ethnographic work particularly emphasizes the method of participant-observation as appropriate to its pursuit of holism, by which Cresswell (1998:61) means “pulling together all aspects learned about the group and showing its complexity.”

A commitment to a qualitative, ethnographic approach in this case has many corollaries. Given the relational nature of “serodiscordance,” holism requires that we include not only the seropositive individual, but also his or her partner. It also suggests that the social world surrounding HIV serodiscordant relationships may well constitute a significant influence on
them and should be studied. Indeed, a foundational assumption of anthropology posits that people’s behaviors, beliefs and values are driven by and derive meaning from wider cultural processes and frameworks—and cannot be explained without reference to those frameworks. As such, rather than considering just the treatment locale, as is usually done, we must widen our field of view. This allows us to recognize that members of serodiscordant couples are much more, and much more complicated, than the strictly biological entities corresponding to positive and negative results of a blood test.

Finally, the injunction to understand the emic perspective remits us to the biocultural nature of human existence. Every serodiscordant couple shares a biological characteristic, namely the respective presence and absence of the human immunodeficiency virus in the blood of the seropositive and seronegative constituent members. However, HIV serostatus, and the risk of seroconversion for the uninfected partner, acquire meaning in cultural contexts; these meanings must be explored, rather than presumed. Hence, this research complicates the perspective on risk typically found within the social science and public health literature by asking what risk means, and positioning that meaning as the result of negotiations undertaken amidst the complex totality of couples’ lives. In that this study focuses on risk-as-social-process, following Douglas and Wildavsky (1982), rather than risk-as-outcome, it illustrates Podolefsky’s (2011:187) assertion that “Anthropological thinking is a habit of mind that begins by questioning fundamental categories of meaning.” This study’s unique contribution to the literature is in taking the biocultural nature of serodiscordance seriously and employing a holistic, ethnographic approach to explore it. The ultimate aim of the research is to produce knowledge that may be applied both to improve HIV treatment for existing patients and aid in efforts to prevent future transmission. Employing a new way to look, perhaps we will discover new things to see.
Foundational Assumptions

The literature review conducted prior to undertaking fieldwork provided a set of empirical expectations and a theoretical point of departure for the research. Specifically, it was expected that a sizable proportion (25-50%) of HIV-serodiscordant, heterosexual couples in this study would not consistently try to prevent HIV transmission, in accordance with the literature on serodiscordance (e.g., Melo et al. 2008; Maksud 2007; Guimarães et al. 2001; van der Straten et al. 2000). HIV prevention practices in general were assumed to be the product of negotiation between the members of the couple, and ultimately stem from the way they understood and prioritized the “risk” of HIV transmission. Therefore, to the extent HIV prevention did not consistently figure in a couple’s sexual practice, at least one member must have conceptualized risk in a way that differed from biomedical recommendations.

Although the social science literature on HIV/AIDS in Brazil does not generally question the undesirability of risk in relation to health, it abounds with factors and forces that are seen as constraining certain individuals’ and groups’ power to minimize their exposure to risk. As previously discussed, these include poverty, violence and insecurity, discrimination, and Brazilian notions of gender and sexuality, respectability, fidelity and trust (Biehl 2007; Goldstein 2005, 2003, 1994, 1992; Knauth 2007, 1997a, 1997b; Maia et al. 2008; Maksud 2007; da Matta 1984; Santos et al. 2002; Scheper-Hughes 1995; Seffner 1995). The theoretical move of framing risk as a social process (Douglas and Wildavsky 1982) requires us to question the unidirectionality of this posited relationship. These concurrent threats and considerations, rather than being limitations on an assumed desire to minimize risk, may actually shape what risk

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56 This “negotiation” must be broadly construed, since intracouple power dynamics (particularly those stemming from access to resources, serostatus, and gender) may confer decision-making authority on one member, while constraining the other. Hence, a couple’s practice may not equally reflect the wishes of both partners.
means. Previous research is useful, therefore, if turned on its head. In fact, from among the plethora of factors previously conceived of as limits to agency, a limited number—those considered most likely to be relevant in context—were taken as angles from which to explore the research questions that orient this project.

**Research Questions**

The following research questions guided the selection and application of research methods:

RQ1: What place does HIV occupy in the everyday lives of a sample of heterosexual, HIV-serodiscordant couples in Porto Alegre, Brazil?

RQ2: How is risk, specifically the risk of HIV transmission, constructed and negotiated by these couples?

RQ3: More specifically, do these couples conceive of risk for HIV or the virus itself as an opportunity (Zaloom 2004) or a commodity (Crane et al. 2002, Abadía-Barrero 2002,) that can be exchanged for goods, services, or social inclusion/status? To what extent do they engage in what has variously been called biological or patient-citizenship on the basis of HIV/AIDS (Petryna 2002, Biehl 2007)?

Of particular interest, in reference to the questions above, was the impact of the following factors: serostatus; exposure to biomedical formulations of risk; economic considerations, particularly each couple’s financial situation and assistance offered by the Brazilian government; and culturally-specific concepts of gender and sexuality, including the importance of reproduction. While the data reported in this dissertation are by no means limited to the foregoing concerns, those topics do provide a focus, intended to ensure a measure of comparability between the otherwise-variable couple sketches (see Chapter 5). In essence, I expected HIV prevention efforts within serodiscordant couples to be inconsistent when the risk of transmission of the virus was not understood as a preeminent concern. I thought the priority accorded this risk would be minimized when: other threats to the couple’s wellbeing (whether
physical, economic, or psychological) were perceived as more immediate and serious and/or when HIV prevention entailed transgression of cultural norms.

Research Funding

This research occurred over seventeen months, during the period of May 2007-July 2010, and had several sources of funding. Financial support covering the entire period of fieldwork came from the University of South Florida’s (USF) Presidential Doctoral Fellowship. In addition, preliminary fieldwork, conducted in May and June of 2007, was partially financed through USF’s College of Public Health as a component of the Master of Public Health degree in Global Health. The longest and most intensive period of fieldwork for this dissertation, from March to December of 2009, was financed by a Fulbright Hays Doctoral Dissertation Research Abroad Fellowship (grant number P022A080073). Finally, the USF PDF was the sole source of funding for a third period, from January to July of 2010. I gratefully acknowledge this support.

U.S. Research Clearance

Prior to departure for the field site in February of 2009, research clearance was sought and obtained from the Social and Behavioral Institutional Review Board of the University of South Florida (IRB #107520, see Appendix). The project was granted expedited review due to its classification as a “minimal risk” study. Although HIV-positive individuals have been characterized by some scholars as constituting a “vulnerable population,” participants in this study were recruited in treatment contexts, thus limiting the recruitment pool to individuals who had already assumed some risk of being identified as seropositive. Measures such as maintaining the confidentiality of individual’s participation (from physicians) and statements (from partners), storing signed consent forms separately from study data (which was largely de-
identified), and the use of password-protected data storage, were taken to protect the serostatus of all participants.

Site Selection and Brazil Research Clearance

It was during my first trip to Porto Alegre in 2007 that I first visited the clinic eventually chosen as the couples recruitment site for this study, and consulted with Dr. Daniela Riva Knauth, an expert on women and AIDS in the area, about possible dissertation topics; these contacts proved indispensable upon my return. After spending a few days observing at the clinic in 2007, I asked longtime members of the staff about the requirements for conducting research there; their answers suggested that obtaining permission was a fairly informal affair, and that personnel were accustomed to dealing with researchers.

Dr. Knauth had suggested several research topics she considered to be of interest to stakeholders in the city, serodiscordance among them. After reviewing municipal epidemiological data on HIV transmission, it became clear that heterosexual transmission was a pressing concern. Hence, heterosexual serodiscordant couples were selected as the focus of this dissertation. A subsequent review of the literature raised the polyvalence of the concept of “risk,” including the potential for the commodification of HIV and the construction, by some populations, of risk as an opportunity (Crane et al. 2002; Abadía-Barrero 2002; Zaloom 2004; Leclerc-Madlala 2006), or as a venue for claiming citizenship (Biehl 2007).

Given these contours of the project, recruiting from the patient population of the clinic I had already visited seemed a suitable choice for this study. As the oldest municipally-run HIV/AIDS clinic in Porto Alegre, it was well-established, had a large patient population, and frequently drew low-income patients. When I returned to the clinic in 2009, things were much as before, with one significant exception. No longer was research permission something that could
be obtained from staff on-site. In order to access the clinic’s patients for recruitment, it was now necessary to have the study approved by the City Health Department’s Comité de Ética em Pesquisa (CEP, or Research Ethics Committee). In order to submit the required paperwork for this application, I had to obtain consent from the clinic director. The director was not someone I had met in 2007. He was, I would learn during my time at the clinic, a good doctor, punctual, thorough; he was also a very cautious manager. Over the course of meetings in March and April of 2009, I explained and submitted in writing the overview of my proposed research. I also gave a short presentation at a staff meeting and formally requested their permission and assistance. At each of these meetings I expected the director to sign the CEP paperwork, as he never gave any objection to the work I outlined for him (particularly since I was not proposing to use clinic space to conduct data collection activities). It was not, however, until the first full week of May that I got his signature.

In the intervening weeks, I had been preparing my study protocol for submission. In contrast to the USF IRB, the CEP required a written proposal rather than answering specific questions about the research; submissions were sent to volunteer reviewers. Because written Portuguese differs dramatically from the spoken Portuguese of even very educated speakers, I contracted the translation of the most theoretically dense portions, fearing time would be lost over merely linguistic errors. I visited the CEP office (staffed by one volunteer and two, new, part-time, student interns, and only open to researchers on Wednesdays) on three separate occasions as I prepared these materials, for general guidance and format and content checks. The staff member was supremely helpful; I submitted my application for review on 6 May 2009.

The formal response from the anonymous study reviewer arrived just over a month later. The reviewer listed seven principal concerns to be addressed before the review could continue.
Among these were: failure to employ sufficiently academic Portuguese; an unacceptably ambiguous study title; inclusion of methods and questions that—in the reviewer’s judgment—were too wide-ranging to correspond to the study’s objectives; insufficient sample size; and the omission, in the list of example questions for the semi-structured interview guide, of any question requiring participants to explain “risk.”

These concerns seemed to me to stem from a failure to grasp the true ethical complexity of the study, and a general lack of understanding of qualitative research. To discuss just one example, the reviewer protested that the study’s working title, “Risco, casais, e profissionais de saúde em Porto Alegre, Brasil” (Risk, couples, and health professionals in Porto Alegre, Brazil), was unethical in that it did not make explicit reference to “HIV serodiscordant couples,” the subject of the research. This level of specificity was seen as my duty to the scientific community. I explained that my primary ethical obligation was, in fact, to the participants of my research. Since I was required to leave a written copy of the informed consent document (including the title of the study) with each participating couple, the ambiguity of the title was a deliberate attempt to safeguard their privacy. It was easy to imagine inadvertent circulation of that piece of paper resulting in a potentially disastrous disclosure of the couple’s HIV status. I argued that all reasonable accommodations should be made to avoid such harms to participants, and that interested members of the scientific community could easily access the keywords and abstract for the study, which provided fuller details. After resubmitting the required materials, my application was formally approved on 5 August 2009.

**Research Timeline**

Phase One: Pre-dissertation field work (May and June 2007)

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57 The most challenging and time consuming aspect of the conditions for continuing review was the linguistic component. Even the sections I had paid to have translated were marked for revision. I am indebted to Marcelo Meier and Dr. Daniela Knauth for assistance with revisions.
Phase Two: Research Clearance and Site Selection (December 2008-August 2009)

Phase Three: Institutional Mapping (March-August 2009)

Phase Four: Site-specific work and Couples Interviews (August-December 2009)

Phase Five: Couples follow-up (January-June 2010)

Summary of Field Methods

In order to understand processes of risk construction among serodiscordant couples in Porto Alegre, it was necessary to determine what exactly was at stake in potential seroconversions. Given the exploratory nature of this dissertation, data were collected using basic anthropological methods of naturalistic and participant-observation and interviewing. Research was conducted with three target populations: representatives of state- and municipal-level institutional actors, clinic-level practitioner and patient populations, and individual HIV-serodiscordant couples. Targeting these three scales was intended to produce a “vertical slice” (Nader 1980) of what João Biehl called “the world of AIDS” (personal communication, 29 March 2008) in Porto Alegre, which would provide adequate context for understanding couples’ experiences and decisions. The state and municipal levels were approached through Institutional Mapping, which consisted of observations and key informant interviews. Clinic-level work was conducted with professionals and patients in one municipal clinic (see above), and included observations, formal practitioner interviews, and informal patient interviews. Recruitment for serodiscordant couples also occurred at this site. Finally, the HIV-serodiscordant couples component was comprised of participant-observation and sequential interviews conducted outside the clinic context. To better orient the reader, the constituent segments have been labeled in accordance with the outline below.

Detailed Reporting of Methods
I. Institutional Mapping
   a. Observations
      i. State- and Municipal-level Organizations and Actors
         1. Controle social and Government
         2. Secretaria Municipal de Saúde (City Health Department)
      ii. Therapeutic Contexts
         1. Serviço (clinic or treatment locale) visits
         2. HIV/AIDS Counseling training
         3. Unidade Básica de Saúde (UBS)-based support group attendance
      iii. HIV/AIDS-related non-governmental organizations
   b. Key Informant Interviews with Representatives of State- and Municipal-level Organizations
      i. Civil Society
      ii. Biomedical and Public Health professionals

II. Clinic-level work
   a. Ethics and H1N1 Delay
   b. Observations
   c. Practitioner Interviews

III. Serodiscordant Couples Component
   a. Vignettes
   b. Eligibility and Recruitment
   c. Challenges in Participant-Observation and Sequential Interviews

Institutional Mapping

As entrée to the world of HIV/AIDS, I conducted “institutional mapping” in Porto Alegre (João Biehl, personal communication, 29 March 2008). By this I mean developing an understanding of the flows of financial, material, and human resources oriented to the epidemic, as well as the power relations that both inhere in and direct such allocations (described in detail below). Knowledge of the political-economic geography of HIV/AIDS was a prerequisite for understanding what infection might mean to serodiscordant couples, and specifically what seronegative members might stand to “gain” from seroconversion, in the sense of possible HIV commodification. This approach included observations and key informant interviews with municipal and state services, entities, and key players as well as civil society counterparts. The extensiveness of the reporting in this section details the basis of claims made about the research context; most of these data are not reported in the dissertation but await future analysis.
Observations: *Controle Social* (I.a.i.1)

Initially, through contacts at the municipal health surveillance unit (*Coordenadoria Geral de Vigilância em Saúde-Porto Alegre*, CGVS) and the *Universidade Federal de Rio Grande do Sul* (UFRGS) Anthropology Department, I obtained access to municipal-level *controle social* meetings. *Controle social* (literally, “social control”) is a function exercised by government-civil society hybrid groups called *conselhos de saúde* (“health councils”—these were mentioned briefly in the Setting chapter). The composition and the responsibilities of these councils are Constitutionally-mandated, and given fuller elaboration in Law 8,142 of 28 December 1990; their importance, not likely to be immediately apprehended by those unfamiliar with the structure of SUS, deserves stating here.

*Conselhos de saúde* must be composed of "representatives of SUS users, service providers, administrators and health professionals”; they have a “deliberative,” and auditing role in the health system, being “fora that guarantee popular participation in the supervision and formulation of strategies for the public application of health resources” (Ministerio da Saúde 2006:12). These are not simply advisory boards. Law 8,142, Article 1 includes a section that specifically stipulates: “representation of [SUS] users…will be equal in relation to that of the other segments,” and “representation” confers decision-making power (CMS 2007:7). It is through the work of *conselhos* that “the permanent mobilisation of civil society” is evidenced, and the concept of human rights as the basis of SUS is to be achieved and defended (CNAIDS 2010:11). The importance of these bodies is more than just ideological, however. In order for a municipality or state to receive a financial distribution from the Federal Ministry of Health

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58 Other types of conseilhos also exist and exercise similar functions within their respective domains (e.g., “environment”).
(which accounts for half of all government health spending in Brazil), it must have a corresponding *conselho* (CMS 2007:9) with which it is in good standing.\(^\text{59}\)

I attended seven plenary sessions of the *Conselho Municipal de Saúde* (CMS, or City Health Council) over the course of fieldwork, learning that the CMS and the *Secretaria Municipal de Saúde* (SMS or City Health Department) had what could be diplomatically characterized as a “tense” working relationship. During these encounters, I discovered the existence of a committee of the CMS called the *Comissão DST/AIDS* (STD/AIDS Commission), which is devoted to *controle social* relating specifically to HIV/AIDS and other STIs. In theory, members of this committee collaborate with the SMS employees responsible for the *Política de DST/AIDS* (essentially, STI/AIDS policy; “the *Política*” is also used to refer to the group responsible for coordinating and executing municipal action on HIV/AIDS), particularly in the development of the Plan of Actions and Goals (PAM). The Commission also studies the STI/AIDS section of the SMS’s annual report and issues a recommendation to the wider CMS as to whether it should be approved or not (approval clears the way for the health department to receive resources from the Ministry of Health).

In practice, however, these functions had not been fulfilled for at least a year, due to what members of the Commission described as their exclusion from the planning process, and problematic communication with the Director that had been ongoing since 2007 (fieldnotes, 9 June 2009). The relationship between the *Comissão* and the *Política* during this time was acrimonious. Many members of the Commission were activists, representing NGOs that were overtly critical—among themselves and in the local media—of the director of the *Política* (who

\(^{59}\) Of course, this is the way the system is supposed to function. Dr. Chris Gibson (personal communication) has documented a great degree of variation in the quality of relationship between *conselhos de saúde* and the government entities they ostensibly oversee, and in the application of laws conditioning the distribution of resources on *conselho* approval.
also had a long history of HIV/AIDS activism in the city). They complained that the application for funding their organizations depended on to conduct prevention efforts (in accordance with the role envisioned for civil society groups by the National Program) had not been made available, and other activities for which they usually were reimbursed by the Política were not being supported. The Director, for her part, claimed that the structure of the SMS itself—including the radical downsizing to which the Política had been subjected only four years previously—often constrained possibilities for action. She also noted that many of the activists were intransigently opposed to the approach to prevention the Política had taken, which she saw as holistic. In contrast, the activists wanted to pursue interventions targeting specific groups, like CSWs, MSM, seropositive individuals, which their respective organizations would be well-positioned to carry out, but which would require the transfer of resources from the Política. In her view, the Commission simply refused to collaborate, instead demanding inclusion on its own terms. When I began attending these meetings, a lawsuit had been filed to compel the Director to attend the Commission meetings, and the PN-DST/Aids was auditing the Política’s finances.

Thus, the Commission’s effectiveness was limited, but it was still a place where activists, health workers, and administrators interacted and brought strategies and plans, current actions and urgent problems to each other’s attention. I attended six of their meetings.

Many of the stakeholders active in the CMS regarding HIV/AIDS issues were also active at the state level, and they invited me to observe a plenary meeting of the Conselho Estadual de Saúde (CES, or State Health Council) featuring a proposal for MSM-focused HIV prevention. In addition to that plenary, I also attended 3 meetings of CES’s AIDS advisory council, which serves the same function at the state level that the Comissão DST/AIDS does within the municipal health structure.
My presence at such meetings served to acquaint me with the organizational structure, funding, and policies regulating HIV-related services in Porto Alegre, as well as offering a window onto the interests and politics behind policymaking. This was the venue at which stakeholders—both individual and institutional—made claims about what they and others had accomplished (or failed to accomplish) on the ground. These claims were asserted in terms of the public’s right to health and the government’s responsibility to provide access. As such, these meetings were my introduction to the use of rights-based discourses pertaining to HIV/AIDS. Just as importantly, however, these meetings introduced me to key actors on the city’s HIV/AIDS stage. These individuals often became key informants, provided contacts in various other HIV/AIDS-related organizations, and frequently explained current SUS policies and entities to me.

**Observations: Secretaria Municipal de Saúde (I.a.i.2)**

Because the municipal and state *conselhos* and their subcommittees on HIV/AIDS meet in, respectively, the buildings that house the SMS and the SES, I had visited these government installations multiple times, particularly the SMS. I specifically visited the SMS Planning Department—housed upstairs from the area allotted to the *Conselho*—however, on four separate occasions. The first visit was made in hopes of participating, alongside *Política* employees, in a seminar on HIV prevention that was being made available in real time over the Internet (all of the employees claimed to have no prior knowledge of this event). The subsequent three visits were made to conduct interviews with health department employees. More extended observations in this context were not possible.
Observations: Therapeutic Contexts (I.a.ii.1)

Though the mission of Brazil’s SUS is to provide “universal and equal access to health services,” observations at CMS meetings revealed public perceptions of unacceptably large variations in infrastructure and services offered throughout the public health system, even between ostensibly equivalent units. In order to ascertain the degree to which such variation characterized locations where Porto Alegre’s AIDS patients received treatment, six different therapeutic contexts were visited. These six were chosen for their historical importance and name recognition, their geographic dispersion throughout the city (see Figure 4.2, below) and the willingness of administrators and staff to allow a visit. They included sites administered by city (n=2), state (n=2), and federal (n=1), as well as private entities (n=1). Repeated visits were made to two of these sites (federal and the city site that served as the recruitment site for the couples discussed in this dissertation); all others were visited only once. These single visits included a short time (5-10 minutes) spent in waiting areas, a tour of the facilities that ranging from 10 minutes to 2 hours, and a formal or informal interview with staff member(s). For description of the more extensive participant-observation conducted at the couples recruitment site, see below.

HIV/AIDS Counseling (I.a.ii.2)

I also completed a course in HIV/AIDS counseling, offered at the Pontifícia Universidade Católica of Rio Grande do Sul (PUCRS). This course was taught by the same instructor, in the same format and covering the same material as a training course offered to selected workers in the health system in preparation for the proposed decentralization of treatment for asymptomatic HIV-positive individuals. Although permission to take the course with these employees (rather than in the open enrollment section) was requested, it was denied. Nonetheless, a sizable minority of students in the section in which I enrolled was employed by
SUS. This training provided a unique window into the health system’s attempt to enculturate workers who didn’t normally encounter HIV patients.

Figure 4.2: Participant Observation Map

Support Group Meetings (I.a.ii.3)

In addition, in order to better understand how some of the city’s most marginalized populations experience and talk about the health care system, over the course of several months (from 1 April 2009 to 22 July 2009) I attended fourteen meetings of a support group for individuals suffering from alcoholism who were at risk of, or currently in what Brazilians call situação de rua (lit., “a street situation”—essentially homeless). This group met weekly in the Unidade Básica de Saúde (UBS, or Basic Health Unit) housed in the same health center that
contains the study’s couples recruitment site. The group was led by a doctor who worked at the UBS; he was assisted by a nutritionist who also worked at the UBS, and a friend of his (a former alcoholic who was in recovery). The meetings lasted for 90 minutes; attendance varied from 0 to 7 participants (in addition to some combination of facilitators) per meeting. A total of 12 individuals attended the meetings at which I was present: three women and nine men.

The doctor (when present) began the meetings by asking what “good things” had happened to the members during the previous week. A topic that always provoked more discussion, however, was the challenges they had faced. Although the doctor and his friend asked about the participants’ current alcohol consumption patterns at each meeting, the doctor particularly seemed to believe that expressing calor humano (literally, “human warmth”) and listening to what those in attendance wanted to talk about was important. What the participants wanted to talk about, by far, was the details of their everyday lives. These details were conveyed through stories that usually revolved around their attempts to deal with bureaucratic and health problems, and to earn money. These stories dominated the meetings.

My observations and interactions with this group were fundamental to the rest of my research in two ways. First, I realized just how significant the linguistic barrier was that separated me from this population (and presumably others like it): they easily understood me, but I frequently could not understand the conversations they had amongst themselves. Although my comprehension improved over time, and varied according to the individual speaking, it never became effortless. Nonetheless, listening to their speech did teach me new vocabulary; grammatical and pronunciation patterns particular to impoverished Porto Alegrenses who lacked formal education; and ways of expressing emotion that proved useful subsequently.
Second, my presence in these meetings allowed a glimpse into the life of a segment of Porto Alegre’s population that would otherwise have been inaccessible to me. I had come to the field motivated by my desire to understand what it was like to live in an HIV-serodiscordant couple, but also specifically to investigate whether the risk of HIV transmission might be seen, by some populations, an opportunity, whether an AIDS diagnosis was treated as a commodity to be exchanged for resources, or an opportunity to claim “citizenship” from the government and civil society. Populations amongst whom the literature (Abadía-Barrero 2002; Biehl 2007) suggested this dynamic might be operating lived in extremely precarious situations. I attempted to include couples living in roughly comparable conditions in my research sample by recruiting from a clinic located in the middle of one of Porto Alegre’s vilas—the same vila where the members of the support group spent most of their time. The support group members, however, were far more marginalized than the couples I eventually recruited; doing excruciatingly poorly remunerated work for which demand was highly unstable (if they had work at all), they often slept on the street. I had been trying to recruit participants from the lower portion of Porto Alegre’s socioeconomic ladder; these folks had been pushed off the bottom-most rung.

Observations: HIV/AIDS-NGOs (I.a.iii)

The historical importance of NGOs in Brazil’s HIV/AIDS epidemic, as well as current procedures for distributing HIV-prevention resources, suggested the inclusion of NGOs as a key research context for understanding the stakes of seroconversion for Porto Alegre’s HIV-serodiscordant couples. A strategy of criterion-based selection (LeCompte and Schensul 1999:113) was used to identify six “ONGs AIDS,” or HIV/AIDS-related non-governmental organizations, to be visited. Entities were chosen on the basis of their current high profile or past prominence in the city’s AIDS movement (for more details, see Table 4.1, below; all names of
NGOs are pseudonyms). Most of these organizations were in a financially difficult period, due to the lack of funds normally allocated by the SMS for HIV prevention projects. Exceptions to this trend were Casa Vocação, which is financially supported by a religious order, and (to a lesser extent) C&S, which obtains significant funding from external sources. Visits lasted between 1 and 3 hours and typically included a tour of the facilities and a formal or informal interview with NGO staff. At Casa Vocação I also observed an afternoon of service provision.

Table 4.1: HIV/AIDS NGOs Visited

<table>
<thead>
<tr>
<th>Organization Name</th>
<th>Mission</th>
<th>Orientation/Focus</th>
<th>Is HIV/AIDS the specific focus of the NGO?</th>
</tr>
</thead>
<tbody>
<tr>
<td>EVA</td>
<td>Defense of Human Rights: combat racism and sexism</td>
<td>Activist: Targeted population: Afro-Brazilian women (anti-violence, self-sufficiency, empowerment)</td>
<td>No</td>
</tr>
<tr>
<td>C&amp;S</td>
<td>Defense of Human Rights: promote respect for sexual diversity</td>
<td>Activist: Targeted population: LGBT* (arts, education, legal) *At time of fieldwork, PLWHAs were not an explicit focus</td>
<td>No*</td>
</tr>
<tr>
<td>Casa Vocação</td>
<td>Vocation: Service to AIDS patients</td>
<td>Religious: Targeted population: AIDS patients (support services, material assistance)</td>
<td>Yes</td>
</tr>
<tr>
<td>NPP</td>
<td>Network for HIV-positive individuals in POA</td>
<td>Activist: Targeted population: HIV-positive individuals (advocacy in health and political rights)</td>
<td>Yes</td>
</tr>
<tr>
<td>GPP</td>
<td>Information and services for CSWs</td>
<td>Activist: Targeted population: Commercial sex workers (distribution of condoms, information)</td>
<td>No</td>
</tr>
<tr>
<td>PAPA</td>
<td>Eradication of HIV/AIDS, valorization of human rights</td>
<td>Activist: General population: Support for/Execution of prevention activities Targeted population: Provide support services for HIV-positive individuals</td>
<td>Yes</td>
</tr>
<tr>
<td>GERA</td>
<td>Combat HIV/AIDS epidemic through service and research</td>
<td>Academic: Targeted population: Policy makers and researchers (Conduct AIDS research, Offer training in relevant research methods)</td>
<td>Yes</td>
</tr>
</tbody>
</table>
In addition to site visits, I attended a day-long meeting of HIV/AIDS NGOs from throughout Rio Grande do Sul, held in preparation for similar national-level meetings; a 2-day seminar on the rights of HIV-positive individuals, organized by NGOs and figures of importance in the city’s AIDS movement; and a protest outside the SES on World AIDS Day 2009.

**Key Informant Interviews (I.b)**

Key informant interviews were semi-structured, conducted during many of the aforementioned site visits with two different groups: representatives of HIV/AIDS-related civil society and a more heterogeneous group that included public health and biomedical professionals. Criteria for inclusion as civil society key informants included current involvement in the HIV/AIDS movement, knowledge of movement history (at least five years) in the Porto Alegre metropolitan area, between the ages of 18 and 65, and capacity to give informed consent to participate. For biomedical or public health officials, inclusion criteria included current employment or employment within the past year as a biomedical or public health professional with experience in the realm of HIV/AIDS, practice in the Porto Alegre metropolitan area, between the ages of 18 (although it is likely that no one under the age of 24 would satisfy the other eligibility requirements, by setting the lower limit at 18, I merely highlight that all participants had attained the age of majority) and 65, and capacity to give informed consent to participate.

These interviews covered the historical development and future trajectory of local responses to the AIDS epidemic, assessments of those responses (including specific policies, successes and failures), perceived needs and barriers to treatment/adherence, and any experiences with serodiscordant couples. The audio from these interviews was digitally recorded. With the exception of one interview conducted with two municipal health department
Table 4.2: Policy & Treatment Informants

<table>
<thead>
<tr>
<th>Participant (Organization or occupation, gender)</th>
<th>Civil society, Public health, or Biomedical</th>
<th>Location and Date of Interview</th>
<th>Duration and Modality of Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>C&amp;S, lawyer, male</td>
<td>Civil society</td>
<td>Workplace (NGO), 14 August 2009</td>
<td>1h6m, Individual</td>
</tr>
<tr>
<td>Casa Vocação, priest, male</td>
<td>Civil society</td>
<td>Workplace (NGO), 28 August 2009</td>
<td>1h1m, Individual</td>
</tr>
<tr>
<td>NPP, activist, male</td>
<td>Civil society</td>
<td>Workplace (NGO), 14/17 August 2009</td>
<td>57m, Individual</td>
</tr>
<tr>
<td>GERA, director, male</td>
<td>Civil society</td>
<td>Workplace (NGO), 4 May 2009</td>
<td>1h11m, Individual</td>
</tr>
<tr>
<td>CMS and CES, activist, female</td>
<td>Civil society</td>
<td>Workplace (SES), 9 July 2009</td>
<td>1h32m, Individual</td>
</tr>
<tr>
<td>CMS leadership, male</td>
<td>Civil society</td>
<td>Workplace (SMS), 8 May 2009</td>
<td>2h45m, Individual</td>
</tr>
<tr>
<td>CES, activist, architect, male</td>
<td>Civil society</td>
<td>Workplace (SES), 10 August 2009</td>
<td>1h16m, Individual</td>
</tr>
<tr>
<td>CGVS employee, female</td>
<td>Public Health</td>
<td>Residence, 19 May 2009</td>
<td>4h, Individual</td>
</tr>
<tr>
<td>SMS DST/AIDS employee, female</td>
<td>Public Health</td>
<td>Workplace (SMS), 8 May 2009</td>
<td>1h37m, Individual</td>
</tr>
<tr>
<td>SMS DST/AIDS employee, female</td>
<td>Public Health</td>
<td>Workplace (SMS), 7 December 2009</td>
<td>1h20m, Joint (with colleague)</td>
</tr>
<tr>
<td>SMS DST/AIDS employee, female</td>
<td>Public Health</td>
<td>Workplace (SMS), 7 December 2009</td>
<td>1h20m, Joint (with colleague)</td>
</tr>
<tr>
<td>SMS Planning Director, psychologist, female</td>
<td>Public Health</td>
<td>Workplace (SMS), 28/29 May 2009</td>
<td>39m, Individual</td>
</tr>
<tr>
<td>State AIDS clinic, physician</td>
<td>Biomedical</td>
<td>Workplace (clinic), 29 May 2009</td>
<td>1h29m, Individual</td>
</tr>
<tr>
<td>City AIDS clinic, physician</td>
<td>Biomedical</td>
<td>Workplace (clinic), 12 August 2009</td>
<td>56m, Individual</td>
</tr>
<tr>
<td>Federal hospital, Infectious disease physician</td>
<td>Biomedical</td>
<td>Workplace (hospital), 26 November 2009</td>
<td>Notes, Individual</td>
</tr>
</tbody>
</table>

employees, all interviews were one-on-one, and varied from 39 minutes to four hours. Most (n=14) interviews were conducted in the workplace, although one was conducted in the
interviewee’s residence (this alternate location was used to eliminate competing demands on interviewee’s time and to allow more freedom in response).

Criterion-based selection (LeCompte and Schensul 1999:113) was again the strategy applied to the eligible pool of civil society actors and public health and biomedical personnel to produce the sample of 15 interviewees. They were chosen for their prominence on Porto Alegre’s HIV/AIDS stage and willingness and availability to participate. These individuals either represented organizations that were well-known in the city’s AIDS movement or had personally become symbols of the fight against the epidemic. A total of seven prominent representatives of HIV/AIDS-related civil society and eight professionals responsible for HIV policy and treatment in Porto Alegre contributed key informant interviews. Further details can be found in Table 4.2.

**Clinic-level work**

**Ethics and H1N1 Delays (II.a)**

As described above, within the first month of the researcher’s arrival in Porto Alegre, the primary study site had been chosen for the clinic-specific and couples-recruitment portion of the project: the oldest municipal STD/AIDS clinic. Work at this location, however, could not begin until formal permission was obtained from the relevant ethics committee. Clearance was granted in August of 2009.

Unfortunately, even after formal permission was obtained, circumstances delayed initiation of the research. Near the end of April 2009, the World Health Organization declared the existence of a Public Health Emergency of International Importance in response to cases of a new strain of influenza documented in Mexico and the United States: Influenza A H1N1. On 25 April 2009, the Brazilian government created the Permanent Cabinet on Public Health
Emergencies in order to better monitor and respond to the situation. Autochthonous transmission was first documented in the middle of July 2009. By 29 July 2009, Rio Grande do Sul had registered 19 of the 56 Brazilian deaths from what many people were still calling “gripe suína” (swine flu), and the extent of the epidemic led the SES to promulgate measures intended to restrict transmission of the virus. These included a two-week delay in the return to classes for public schools (until 17 August 2009), and a ban on elective surgeries (in effect from 26 July-22 August 2009). Deaths were reported until well into September; 190 H1N1 deaths had been documented of 25 September 2009.

The perceived gravity of this situation led to a delay in beginning sustained observations in clinical contexts. The justification for this decision was two-fold. First, immunocompromised individuals, for obvious reasons, were thought to be particularly at risk of contracting H1N1. My presence among concentrated groups of such people would entail our mutual exposure to any microbes any of us were harboring. In the interests of patients’ health, as well as my own, the doctor in charge of the recruitment site mandated a delay. Second, AIDS patients’ hypothesized susceptibility to H1N1 led clinic staff to anticipate being extremely busy during the month of August. Given the many questions that were sure to arise in the initial days of observation, all parties thought it best not to begin my observations just when biomedical personnel were likely to have the least opportunity to explain everyday logistics.

Observations (II.b)

Thus, it was from late August-December 2009 and periodically from January-June 2010 that participant-observation was conducted in the clinic. Two different types of observations

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60 http://www.saude.rs.gov.br/wsa/portal/index.jsp?menu=noticias&cod=47883#
were conducted: waiting area- and practitioner-based observation. The goals were to understand the “normal” flux of treatment for both patients and health professionals, become familiar with the language used in such contexts, and recruit participants for the couple-based portion of the project. Observation and recruitment strategies are treated separately here merely to simplify discussion; all activities were concurrent.63

I engaged in waiting area-based observation as a way to become familiar with the overall operation of the clinic. This was particularly useful in the physical space the clinic occupied prior to 1 December 2009, since one common area saw most patient and practitioner foot traffic that occurred throughout the day. The general procedure for this type of observation was straightforward: arrival; greeting of staff working in and adjacent to the patient check-in area; reviewing the posted appointment lists for each physician; greeting patients in the waiting area; locating a staff member to discuss whether patients scheduled to be seen that day might be eligible for the study. I requested an introduction to any potential research participants encountered during the shift. Then, acting either on a referral from a staff member or purely upon seat availability, I would take a seat in the waiting area to observe.

During my observation periods I began conversations with patients or group of patients by asking whether they had an appointment, who their physician was, and how long they had been receiving treatment at the clinic, etc. More than half of the time people were receptive to these queries, asking doubtfully afterwards if I were a patient or sometimes going straight to the point and asking (equally doubtfully) “Você é daqui?” (Are you from here?). In response, I described myself as an anthropology student from the U.S., conducting a study in the clinic. After some rapport-building talk I asked—if this information had not already been shared—if the

63 For a consolidated and focused reporting of data from clinic-level observations and interviews, please see Appendix IV.
patient had a partner and if that partner was also HIV-positive. Based on my interlocutor’s response, I explained the purpose of the study and asked if s/he were interested in participating or if s/he knew of anyone in a serodiscordant relationship. With eligible and interested participants, I described the study procedures, allowing time for questions and comments.

Once I felt reasonably certain the patient understood what participation in the study entailed, I asked if s/he would consider it, and if his or her partner might also consent. No eligible participant ever refused to participate at this point, and contact information was exchanged to permit follow up with the couple afterward. Eligible and willing couples were accepted into the study as their participation could be scheduled. Since the maximum enrollment for this study was not reached, no couples were turned away on this basis. Upwards of 80% of the patients I spoke to, however, were not eligible for the study, since they were not members of a serodiscordant couple. The conversations I had with them were nonetheless illuminating with regard to the functioning of the clinic, perceptions of individual practitioners and policies, and levels of knowledge about HIV among patients. They also exposed me to narratives about diagnosis, illness, and stigma.

After becoming an accepted presence in the clinic, I asked various practitioners if I could observe their work. Eventually I formally observed anti-retroviral medication being dispensed; patient check-in; condoms and lubricant distribution; two sessions of a support group for HIV-positive pregnant women (although these meetings had been cancelled during the H1N1 outbreak, they were re-instated as summer approached); “adherence check-ups” for patients who were new to, or were having difficulties with adherence to, antiviral medication; and at least eight sessions of patient consults with five different physicians. For my presence during the support group sessions, the adherence check-ups, and appointments with doctors (the only
interactions in which patients might have had expectations of privacy), each individual patient’s consent was sought. I also offered to leave the examination room at any point, although this happened only once. In fact, a more frequent occurrence was being invited by a patient with whom I was conversing in the waiting area to observe his or her appointment with the doctor (when these invitations were accepted, the doctor’s consent was also sought). I expressed my wish to be as unobtrusive as possible during observation sessions, preferably remaining silent and taking notes. Despite agreeing on this point, patients and practitioners alike addressed pleasantries, explanations, and questions to me during most of the consultations for which I was present. These observations were in addition to informal interviews with virtually all clinic personnel.

**Practitioner Interviews (II.c)**

Inclusion criteria for these formal, semi-structured interviews included current employment in the clinic of interest, between the ages of 18 and 65, capacity to give informed consent, and desire to participate. The interviews followed the same guide as those for other public health and biomedical personnel, covering the historical development and future trajectory of local responses to the AIDS epidemic, assessments of those responses (including specific policies, successes and failures), perceived needs and barriers to treatment/adherence, and experiences with serodiscordant couples. The interviews occurred over a period from 25 April 2009 to 27 April 2010. The audio was digitally recorded, ranging from 47 minutes to two hours. All interviews were conducted individually, and most (n=5) were conducted in the clinic, (one practitioner preferred not to be interviewed at work). Purposive sampling (Bernard 2006) was employed, to ensure the representation of several professions. The six professionals included
were two doctors and four non-physicians specialists. They were chosen for their knowledge of the history of the clinic, their familiarity with a large number of the clinic’s patients, and/or their status as the physician of the seropositive member of a couple recruited for this study.

**Serodiscordant Couples Component**

The most intensive component of this study involved participant-observation and sequential interviews with members of willing serodiscordant couples. Though seropositive individuals were screened for eligibility at the clinic selected as the study recruitment site, data collection was to take place in their homes. Observations and interviews were done concurrently or separately (i.e., visiting a couple did not always entail an interview) over the course of several months, providing an extended case study. As Charmaz (2005:529) notes, “Multiple visits over time combined with the intimacy of intensive interviewing do provide a deeper view of life than one-shot structured or informational interviews can provide.” Thus, the design produced a nuanced, emic understanding of the experience of serodiscordance. Given the intensive interaction required with each couple, a limited number of couples (N=6) was recruited.

For each couple, both members were to be interviewed individually and jointly. Interviews centered on the couple’s history and current circumstances, as well as sexual practice; diagnosis, disclosure, and the impact of HIV seropositivity; general perceptions of couplehood and gender; and hypothetical scenarios involving couples and risk for HIV (see below for more details on these hypothetical scenarios). The format for the interviews was semi-structured, using a list of questions to guide the interaction; however, topics were not necessarily addressed in the same way or order by each participant. The interviews were face-to-face and digitally recorded whenever possible.

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64 Providing more detailed information on these interviewees would compromise the confidentiality of their participation. For detailed reporting concerning these interviews, see Appendix IV.
Vignettes

At various points during the sequence of interviews with each dyad, participants heard one (or more) of three hypothetical scenarios involving couples and HIV transmission. They then responded to a series of questions, which asked them to discuss the fictional characters’ emotional reactions to HIV diagnosis; to recommend “next steps” for the protagonists; and to attribute the incident infection to its most likely source, albeit on the basis of incomplete information. These follow-up questions were the same for all three scenarios. The three “vignettes” (for full text, please see Appendices) were created in reference to the context of HIV/AIDS in southern Brazil. Based on scholarly work, especially qualitative studies, they feature details such as routine prenatal testing (Bergenström and Sherr 2000; Kreitchmann et al. 2004) and truckers as a (potential) source of HIV infection (Malta et al. 2006), as well as the intersection of masculinity, sexuality, and risk-taking (Ford et al. 2003; Knauth 2007). They deliberately included opportunities for speakers to address stereotypes (involving gender, commercial sex work) and apply knowledge (for example, modes of transmission, latency period) about HIV/AIDS.

The purpose of this procedure was two-fold. First, it was designed to elicit talk about HIV and HIV-positive people that did not necessarily have as its referent the participant or his or her partner. If an “affective override of cognition” (Foreman 2003) with relation to HIV/AIDS risk, or a lack of personalization of such knowledge (Sobo 1995) were to be found within this sample, a basis for comparing talk about self and others was necessary. This technique seemed likely to bring such contrasts to the fore, if they existed. It also allowed participants who seemed initially reluctant to discuss their own experiences with HIV to broach the topic in a hypothetical context first (potentially facilitating the incorporation of personal elements in their reactions).
Eligibility and Recruitment

Eligibility requirements for participation in this component of the research included the seropositive member of the couple receiving treatment at the clinic selected as the recruitment site; self-identification by both partners, at the time of recruitment, as a “couple” (including married, common-law, cohabiting relationships, etc.); knowledge on the part of both partners of serostatus; current residence of at least one partner in the Porto Alegre metropolitan area; both partners aged between 18 and 65; and informed consent to participate by both partners.

It was recognized from the outset that recruitment for this study would be challenging. The prevalence of HIV-serodiscordant relationships in Brazil is unknown. However, one can assume it to be much lower than estimates from countries experiencing “generalized” epidemics (like parts of sub-Saharan Africa), since Brazil’s epidemic is characterized as “concentrated.” A study conducted in the U.S. (which also has a “concentrated” epidemic) by Kalichman et al. (2002) reported that just 85 of 383 (22%) HIV-positive individuals claimed to have a regular, HIV-negative partner. Based on such findings, I assumed that less than one-third of the patients at the clinic would be eligible for this study. I was faced with the question of how to screen the thousands of people receiving treatment there for eligibility, given time constraints and ethical considerations.

Although I was granted permission to access patient charts, and thereby identify and obtain contact information for potential participants, preliminary discussions with two clinic staff members revealed problems with this approach. First, there was a good chance charts would not contain information on patients’ partners, or that such information might not be current. The only time a question about the serostatus of a patient’s partner appeared in clinic paperwork (and, being institutionalized in this way, was likely to be asked) was on the form completed at the first
ambulatório de adesão appointment (see Chapter 2). Thus, this form would not be present in the charts of patients who hadn’t been prescribed ARVs. In addition, for the clinic’s long-term patients, partner data on this form—if their charts contained such information at all—could be ten or fifteen years old. The second problem was one the clinic staff dealt with on a daily basis: the contact information listed in patient charts, particularly cellular telephone numbers, was often incorrect. More importantly, however, I discarded this approach based on ethical concerns. Telephoning a clinic patient without any previous contact between us meant I was reaching into a life without knowing to whom, if anyone, that individual had disclosed her or his serostatus, who might be in close enough proximity to overhear our conversation, whether such contact might be considered a traumatic intrusion, etc.

Despite its relative inefficiency, the only defensible option seemed to be to personally and individually screen patients physically present in the clinic. This was in fact the strategy employed; as described above, this constitutes convenience sampling. The only restrictions imposed (in addition to the eligibility criteria discussed previously) were: an attempt to recruit an equal number of seropositive men and women, and the exclusion of patients whose speech I could not understand. No couples were excluded on the basis of the desire for a gender balance; the latter consideration presented barriers to communication prior to the establishment of the patient’s actual eligibility, making it impossible to estimate how many eligible couples were excluded on this basis.
Table 4.3: Couples Sample Description

<table>
<thead>
<tr>
<th>Seropositive Member</th>
<th>Seronegative Member</th>
<th>Couple Formation</th>
<th>Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Iara (female, 44)</td>
<td>Jorge (male, 30)</td>
<td>Prior to diagnosis</td>
<td>None (I—1 miscarriage)</td>
</tr>
<tr>
<td>Xavier (male, 45)</td>
<td>Juliana (female, 57)</td>
<td>Post-diagnosis</td>
<td>Multiple previous, none together</td>
</tr>
<tr>
<td>Renato (male, 35)</td>
<td>Milene (female, 30)</td>
<td>Post-diagnosis</td>
<td>M—1 son previous, none together</td>
</tr>
<tr>
<td>Bibiana (female, 33)</td>
<td>Felipe (male, 32)</td>
<td>Prior to diagnosis</td>
<td>B—1 daughter previous, none together (abortion)</td>
</tr>
<tr>
<td>Rita (female, 35)</td>
<td>Adriano (male, 43)</td>
<td>Post-diagnosis</td>
<td>One together (born during research), A—1 daughter previous</td>
</tr>
<tr>
<td>Wílian (male, 50ish)</td>
<td>Pamela (female, 45)</td>
<td>Post-diagnosis</td>
<td>W—6 previous, P—1 previous, none together but all had resided with couple</td>
</tr>
</tbody>
</table>

**Challenges**

As is to be expected, challenges arose during data collection. Overall, observations were less problematic than interviews, although locations and scheduling sometimes had to be improvised. One couple did not have their own home until several months after their participation commenced; they were not comfortable conducting study activities where they lived initially. For four couples, the presence of children or other family members sometimes limited the scope of conversation or activities. Lack of privacy was therefore a significant obstacle. Insufficient time to schedule visits for data collection was also a consideration, particularly for couples recruited later. Nevertheless, in addition to observations at couples’ homes, I was also able to participate in baby showers, birthday parties, barbeques, meals at restaurants, and hospital visits.
Interviews presented more obstacles, both for the reasons mentioned above and others. When both partners were present, it was difficult to conduct an individual interview. Wilian’s scheduled interview, for instance, became a conversation that included Pamela’s contributions because they were both at home that evening. This could also be more subtle; Jorge’s individual interview includes few recorded utterances from Iara, but she was present—and potentially listening—for the duration. On the other hand, obtaining both partners’ participation was sometimes impossible, as in the case of Bibiana and Felipe, (see Table 4.4 for more details).

Table 4.4: Couples’ Component Data

<table>
<thead>
<tr>
<th>Couple (+/-)</th>
<th>Joint Interview(s)</th>
<th>Individual Interviews (+)</th>
<th>Individual Interviews (-)</th>
<th>Additional Interaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Iara &amp; Jorge</td>
<td>(40m)</td>
<td>(1h11m), (1h51m), (notes on 1h initial clinic mtg)</td>
<td>(1h16m)</td>
<td>3 home visits, lunch with Iara’s sister, MSN chat, Orkut</td>
</tr>
<tr>
<td>Xavier &amp; Juliana</td>
<td>(1h37m)</td>
<td>(notes on 1h initial clinic mtg)</td>
<td>(1h46m)</td>
<td>hospital visit, 2 home visits, post-split visit</td>
</tr>
<tr>
<td>Renato &amp; Milene</td>
<td>(1h24m)</td>
<td>(notes on 45m initial clinic mtg), (1h20m)</td>
<td>(1h01m), (1h40m)</td>
<td>4 home visits, Renato’s birthday party</td>
</tr>
<tr>
<td>Bibiana &amp; Felipe</td>
<td>---</td>
<td>(notes on 30m initial clinic mtg), (1h44m), (2h17m)</td>
<td>(1h28m)</td>
<td>Home visit, dinner at a restaurant, Orkut</td>
</tr>
<tr>
<td>Rita &amp; Adriano</td>
<td>(1h05m), (59m)</td>
<td>(2h07m)</td>
<td>(1h13m)</td>
<td>home visit, baby shower, mtg @ clinic</td>
</tr>
<tr>
<td>Wilian &amp; Pamela</td>
<td>(notes), (1h38m)</td>
<td>---</td>
<td>(1h40m)</td>
<td>2 home visits, one mtg @ clinic</td>
</tr>
</tbody>
</table>
Data Analysis and Presentation

Data are presented in two different ways in this dissertation: through so-called “couple sketches” and in two additional chapters linked to the research questions. Such a “bifocal” view is intended to convey context and complexity, while also effectively dealing with the cross-cutting concerns that structured the research. The “couple sketches” aim to present an integral picture of each dyad, emphasizing what I understood to be the specific concerns and dynamics that textured their daily life during the period I interacted with them. Since these particulars were highly variable, the sketches do not follow a standardized format or cover strictly comparable information for all couples. In general, however, certain topics deemed relevant to the focus of the research appear in every sketch, for example, the couple’s history and discovery of serodiscordance, particularly the seropositive partner’s diagnosis experience; their current interactions, including HIV prevention practices; gender dynamics, economic situation, and living conditions. This information is presented both in the interest of holism as well as providing necessary context from which to interpret the subsequent chapters, which address the research questions that animate this project in a more systematic and comparative way. Both approaches rely on the same body of data, but are undergirded by different analytical processes. I report them here as they unfolded: sequentially.

Data reported in this dissertation are drawn primarily from formal (recorded) and informal interviews with, and participant-observation of members of participating HIV-serodiscordant couples. Recorded interviews were transcribed; with the exception of passages that could not be understood, speech was transcribed verbatim (including false starts, repetitions, interruptions, etc.), and relevant sections of fieldnotes were digitized. In order to produce each couple sketch, I collected all the materials pertaining to a couple and began an immersion in
these data by re-reading the fieldnotes. Then I listened to all recorded interviews again, simultaneously reading the transcripts and adding information on tone of voice and conversation dynamics, background knowledge necessary for understanding the recorded speech, and co-occurring events, when relevant. This immersion allowed me to craft a narrative that conveyed an emic perspective. Topics or issues that I frequently encountered or that were spontaneously mentioned by the couple were granted priority in terms of order of appearance and/or space within the sketch. Quotes that were particularly illustrative of participants’ experiences and feelings were identified and inserted in the narrative. This process was repeated for each featured couple. It was at this point that the necessity of substantially augmenting the envisioned political economic framework for analysis became indisputable.

Hence, after completing the couple sketches, the “enhanced transcripts,” and electronic format fieldnotes were uploaded into MAXQDA Plus, Version 10 (2012 VERBI GmbH), a qualitative data analysis software package. Each file was then subjected to an ethnographically-informed, thematic text analysis. Because of the exploratory nature of this research, the search for themes was largely inductive (Bernard 2006:493). It conformed in some degree to a grounded theory approach (Glaser and Strauss 1967, Strauss and Corbin 1990, Charmaz 2006; Markovic 2006), but was specifically guided by strategies suggested by Ryan and Bernard (2003).

The mechanics of analysis entailed re-reading each document, identifying segments of text—ranging in size from a few words to a few paragraphs—that conveyed a central idea, then distilling that idea into a short label. Sometimes this label came from the text itself (in vivo coding, Strauss and Corbin 1990:61-74) and, hence, was necessarily in Portuguese, for example, bloqueio, and normal, which translate as [mental] “block” and “normal,” respectively. These
words were used in particular ways by multiple interviewees, suggesting the existence of “indigenous typologies or categories” (Ryan and Bernard 2003:89). Other labels were my own short-hand for repeatedly-expressed ideas or metaphors (Ryan and Bernard 2003:89, 90), such as “other diseases worse than HIV” or “fight metaphor.” These codes were created as necessary and re-applied to any text that appeared to be an additional expression of the same underlying theme. Upon creating a code, I also created a “code memo” in MAXQDA that contained a rough definition and any exclusion criteria. As additional examples of the code were encountered, code memos were edited as necessary to reflect the evolving analysis.

Not all codes sprang from the texts themselves. As acknowledged by many sources on qualitative methods (e.g., Willms, et. al 1990, Ryan and Bernard 2003, and Bernard 2006) general themes can be derived a priori from a researcher’s understanding—experiential and theoretical—of the particular slice of reality s/he is studying, as well as from the interview guide utilized (if any) in data collection. I employed a handful of such codes in this analysis: gender, economic situation, sex, desire for child, and diagnosis, for instance. For each of these, I wrote a general definition and specified certain exclusions prior to beginning the analysis.

After reading and coding all texts, what I call “first round coding,” the codebook contained 88 codes. However, to ensure that instances of late-emerging themes hadn’t been missed in the earlier-coded texts, a “second round” of coding was necessary. Hence, each text was re-read, additional codes were applied and already-coded segments were revised (in light of code definitions modified in response to concrete examples encountered in the texts) as necessary. After the second round of coding, the codebook was composed of 121 codes (including sub-codes); 35 documents had yielded 2432 coded segments. At that point, the codebook was standardized, based on guidance from an NSF-sponsored Text Analysis workshop.
led by Drs. Clarence Gravlee and Amber Wutich (Text Analysis Workshop, AAA 2011, Montreal, CA), DeCuir-Gunby, Marshall, and McCulloch (2011), and MacQueen et al. (1998).

Not only the coded segments but also the relationships between the codes themselves were scrutinized for what they revealed about participants’ constructions of risk. Following Gee’s (2005:23) notion that discourse is the human attempt to be recognized as a particular kind of “who-doing-what”, this scrutiny involved what he calls the “seven building tasks of language”65 (Gee 2005:11-13). Particularly as these building tasks implicated HIV, contradictory patterns were discovered. Examining these patterns more closely brought to light the diversity of language by which participants referred to HIV transmission specifically. All texts were read again, in search of the various terms employed around this key event; the three most common modes of expression were identified. Each instance of these usages was extracted, forming the body of data that was subjected to the discourse analysis featured in Chapter 6. In addition, the segments coded with Risco (Risk), Normal (Normal), and Benefícios/Direitos (Benefits/Rights) were examined for patterns in terms of speaker characteristics, referent, and content; the findings with regard to the latter code are featured in Chapter 7.

**Epistemological Limitations of the Study**

The sensitivity of the topics considered in this dissertation raises the specter of the well-known disjuncture between what people do and what people say they do (Charmaz 2005:529). Typically, anthropologists attempt to address this through triangulation (Bernard 2006), particularly by combining participant self-reports with direct observations of the behaviors of interest. This kind of “cross-check” was performed for many aspects of interactions between and among biomedical professionals and members of serodiscordant couples. However, as in most

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65 These are: significance, activities, identities, relationships, politics, connections, and sign systems and knowledge.
research that deals with sexual practices (Wight and Barnard 1993), directly observing the negotiation and (non-) use of condoms was not possible. As such, other means of verifying individual reports were employed, including checking individual statements against partner assertions, following-up over multiple data collection sessions, and comparing self-report data to HIV seroconversions and pregnancies. Nevertheless, one must remain cognizant of the implications methodological restrictions have for how we know what we claim to know.

In addition, by choosing to research a given topic in a particular location, researchers are impacted by what it has previously been thought important—or unimportant—to know there. Serodiscordant couples for instance, as discussed previously, constitute an unknown population in this study’s research site because, although AIDS is a notifiable diagnosis in Brazil, there is no systematic attempt to collect data on serodiscordant partnerships. The non-existence of epidemiological data on any scale (Federal, state, city, or specific treatment context) makes it impossible to speak to the representativeness of this sample.

However, this may be less a limitation than it seems, since this exploratory, qualitative study was not designed to produce “generalizable” knowledge. The purpose of this dissertation is two-fold: 1) to produce a fine-grained account of how large-scale social and cultural forces come to be experienced, understood and acted upon in a particular context by serodiscordant couples, and 2) to provide an account of what was learned that facilitates considerations of “transferability.” That is, once the context and the dynamics that operate within it are made explicit, and subsequently linked with specific behaviors, beliefs, and values on the part of research participants, policy makers and health professionals can determine which processes or concepts documented here might be relevant in other contexts.
Finally, although it can be encompassed in the generalizability/transferability discussion above, the epistemological limitation of the study I consider most grievous should be addressed here, both because of its relevance to one of the research questions and its implications for social justice. Relying on recruitment from treatment contexts entails a potentially serious omission from the sample: serodiscordant couples in which the seropositive individual is unable to access, or has decided to forego, treatment. João Biehl (2007:204) has documented what he calls “technologies of invisibility” that render certain classes of individuals far less likely than others to access health services, to be diagnosed with HIV, or be provided adequate follow-up care if diagnosed. The mechanics of such processes is beyond the scope of this chapter; what is essential to highlight here is that these “invisible” patients are often society’s poorest and most marginalized. Thus, relying on “HIV/AIDS patients” as the population from which a sample is drawn produces a systematic gap in any knowledge gained through research.

I attempted to address this blindness by establishing a connection with the USB-based support group for those dealing with addiction to alcohol in a “street situation.” However, the opportunity to dialog about HIV never materialized during meetings and linguistic barriers and safety concerns (often as a result of members’ substance use) kept me from pursuing conversations with these individuals in other contexts. The lack of these particular data has stark implications for my ability to address the commodification of HIV and the construction of HIV risk as an opportunity. It also makes it very difficult for any recommendations drawn from my research to enhance this population’s access to health services they desperately need. In essence, excluding them from the sample serves to reinforce their social invisibility and the injustice they experience every day. While the barriers to their inclusion in this research are understandable, rectifying this omission remains a strong motivation for future research.
Methodological Limitations of the Study

Time Constraints

As discussed above, despite relatively rapid identification of the main site for this research, permission to begin observations and interviews at the clinic, as well as the clinic-based recruitment of HIV serodiscordant couples, was not granted until 5 August 2009. Subsequently, a further two week delay was necessary in light of the risks the H1N1 epidemic potentially posed (both to myself and possible participants). Given that one of the strengths of this project was intended to be follow-up with couples over an extended period of time, the loss of five months was a serious limitation. Although a second extended period of fieldwork (January-June 2010) was added, this trip encompassed the summer months, when Porto Alegrenses are more likely to vacation or have family and friends come to visit and therefore be unable to participate in this study. Accentuating this trend, the period included Carnaval and the 2010 FIFA World Cup tournament, periods during which the city virtually shut down and a holiday mentality reigned.

Limitations of the Sample

The sample reported on in this dissertation is small: six couples. As discussed previously, the size of the sample was in part determined by comparing the time needed to recruit and collect data with each participating couple to the time available to spend in the field. Preference was given to considerations of depth of understanding as opposed to breadth. These issues notwithstanding, how might other scholars judge whether a sufficient number of couples was included? Such small samples are usually justified as having been sufficient to achieve “saturation,” which is defined as “collecting data until no new information is obtained” (Morse 1995:147). However, Charmaz (2005:528) notes that this criterion frequently receives little
critical consideration; questions of “what saturation means and to whom” are left unconsidered (but see Guest et al. 2006).

Thinking along these lines reveals that what exactly “saturation” would mean in the context of this study is unclear. Given the challenges encountered in recruitment for this research, and the foundational assumption that the construction of risk is a social process and must be understood with reference to each couple’s specific context and history, including the number of couples required to achieve “saturation” would have required an impracticably long period of fieldwork. Even turning our consideration to the number of interactions required with each recruited couple, “saturation” proves to be of questionable utility. Sequential interviews and follow-up visits always produced “new information,” even if that information was that the couples had maintained previously reported behavior patterns as they acquired more experience in dealing with the issues raised by their serodiscordant status.

If saturation is an inadequate measurement, then perhaps the objective of the study itself can lead to a more appropriate way of deciding “how many is enough?” as concerns sample size and data collection interactions. The goal of this dissertation was to acquire a deep enough knowledge of sociocultural context and HIV-serodiscordant couples’ experiences to understand and explain the dynamics of risk construction and negotiation as they occurred within each couple. Christians’ (2000:151) summons of “the thick notion of sufficiency” therefore proves relevant, since it, like this study, “seeks to open up the social world in all its dynamic dimensions.” Interpretive sufficiency, as it has been used in the work of Denzin (1989:77), “means taking seriously lives that are loaded with multiple interpretations and grounded in cultural complexity.” Specifically, this means that ethnographic accounts “should possess that amount of depth, details, emotionality, nuance, and coherence that will permit a critical
consciousness to be formed by the reader” (Denzin 1997: 283). I believe the depth of knowledge and degree of engagement achieved with the six couples who comprise the sample for this dissertation will allow readers to form just such a “critical consciousness” with regard to the ways risk is constructed and negotiated within serodiscordant couples.

**Bias**

Several potential sources of bias affected the sample. It was easier to approach patients in the waiting room who had been referred to me by clinic staff. This introduces practitioners’ biases into sampling procedure (specifically when they made referrals based on their memory of particular patients rather than having come across eligible individuals in the course of their daily duties), although the effect of those biases is impossible to determine. The effect of other biases is clearer. As a female, it was easier for me to approach women than men in the clinic waiting area. As a corrective measure, gender parity among seropositive partners in the sample was enforced. Finally, as mentioned previously, those patients whose speech I could not understand were excluded from the sample prior to even ascertaining eligibility for participation in the study. To the extent that I had the most difficulty conversing with patients whose Portuguese differed most radically from the dialect spoken by educated, middle- and upper class Brazilians, this constitutes another systematic bias.

Other biases may have impacted the study after couples were recruited. As mentioned, the proposed data collection activities were too ambitious overall, and the number and quality of interactions with couples were not strictly comparable across the sample (see Couples Component Data Table above). Completion of the planned sequential interview component clearly would have enabled more, and more nuanced, systematic comparisons between cases. More importantly, however, to the extent that it was more difficult for some couples to
participate than others (often due to time and space constraints), fewer data collected may correlate with couples’ experiencing other challenges that may have impacted their constructions of, and negotiations regarding, risk.

In general, the difficulty of cross-gender communication about sexual practice was underestimated in the design of the research. Male participants were much less forthcoming with details about sexual interactions than females, especially when being interviewed individually. The exception to this rule proved unmanageably problematic. Data collection activities with the seropositive male partner in one couple were curtailed in order to limit the amount of time I spent alone with him after he persisted in modes of interaction that were considered inappropriate.

**Conclusion**

The foregoing chapter has provided a detailed accounting of the varied components of this research, the methods used in data collection, and the analytical processes on which this dissertation is based. By applying traditional anthropological methods of participant-observation and interviewing to a wide range of stakeholders, I developed a holistic understanding the “world of AIDS” in Porto Alegre that informed the analysis of the data explicitly reported in Chapters 5-7. As with all research involving sensitive issues, couples, and HIV/AIDS, ethical issues demanded careful consideration, and accountability to various publics.
CHAPTER 5: COUPLES SKETCHES
Introduction

In this chapter, I attempt to give a holistic, yet focused account of the texture of six, heterosexual, HIV-serodiscordant couples’ lives. I do this by offering a “sketch” of each participating couple. While a particular goal is to shed light on the place the virus, and the risk of transmission, occupy for each dyad on a day-to-day basis, the sketches are by no means limited to HIV-related topics. In fact, for most members of the couples I interviewed, there was a “before-and-after” to which they seemed tethered, returning again and again to this break as a resource for interpreting their life experience; yet for only two individuals (both seronegative) in the sample was this incontestably the discovery of (their partner’s) seropositivity. In the majority of cases, more complex dynamics were at play, and the sketches showcase this.

Hence, at times the sketches may appear to the reader to wander, to supply quaint or touching anecdotes rather than “relevant data.” But such a judgment is founded upon the supposition that we know, at the outset, what the “relevant data” are. If the objective is to take the constructed or polysemic nature of “risk” seriously, as it is in this project, such preconceived ideas must be abandoned to the extent possible. It was my goal to engage in a fundamental way with my research participants, ready to whole-heartedly attend to the stories they wished to tell, rather than being always ready to transpose them into a pre-existing framework. I wanted instead to discover their framework, a process that felt something akin to trail running blindfolded, a small sense of which I try to evoke for the reader through the free-flowing form of the narratives.
I recognize that this process of discovery is contingent on the subject positions of the individual participants; the stories told to me are not necessarily the stories that would have been told to a different anthropologist. As a younger-looking, white, blond, able-bodied, female from the United States who loves to talk and is quick to laugh, I played a role in the creation of these narratives that far exceeds merely receiving them. On the other hand, I do not believe that the stories my participants told were exclusively the product of the self they wished to present to someone like me. The academic literature structured my expectations about what dynamics might be important in the field. I strove for a measure of comparability (Guba and Lincoln 2007) in the data across couples and worked with an interview guide as a means to that end.

As such, although the interviews and observations on which this dissertation is based were not entirely uniform, they addressed common topics, including (but not limited to): the temporal relationship between couple formation and the discovery of serodiscordance; meanings of serostatus and understandings of HIV in general; the experience of diagnosis; culturally-specific notions of gender, sexuality, and reproduction in heterosexual, Brazilian couples; social class; and the power relationships that organize all of the above dynamics. Accordingly, the sketches presented here draw from this list and are structured by considerations that I, as a researcher interested in the experience of HIV-serodiscordance in daily life, think relevant.

First, however, just as important as the findings of any research, is its ontological foundation, and attendant epistemological implications. Thus, the next section provides an abbreviated discussion of the approach to discourse that structured data collection and analysis.

Discourse

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66 On “distortion” in interviews, see Quinn 2005:17.
Cultural anthropologists think we can apprehend foundational aspects of culture that produce meaning—even witness their reproduction and modification—through what people do and say. This is in part due to an understanding of discourse as a “constantly emerging and emergent interface between language and culture” (Sherzer 1987:296). I have found it helpful to employ James Paul Gee’s (2005) terminology and methodology of discourse analysis; as such, I give the briefest possible overview below.  

Gee distinguishes between language-in-use (the rules or norms that stipulate what can be meaningful and what cannot), and the totality of discursive production on a given topic. His basic concept, what he calls “little d” discourse, is the use of language “‘on site’ to enact activities and identities” (Gee 2005:7). Language alone, however, is often not sufficient to achieve this goal. Hence, he also employs a notion of “big D” Discourse, which entails “ways of combining and integrating language, actions, interactions, ways of thinking, believing, valuing and using various symbols, tools, and objects to enact a particular sort of recognizable identity” (Gee 2005:21). This D/d distinction is joined by Gee’s notion of Conversations, that is, “all of the talk or writing that has gone on in a specific social group or in society at large around a major theme, debate or motif” as well as knowledge of “the various sides one can take in debates about these issues and what sorts of people are usually on each side” (Gee 2005:22).

Together these concepts are used to argue for the weight of history upon, and inherent dialogism of language. As Bakhtin (1984:202) wrote, “When a member of a speaking collective comes upon a word…the word enters his context from another context, permeated with the interpretations of others….When there is no access to one’s own personal ‘ultimate’ word, then every thought, feeling, experience must be refracted through the medium of someone else’s

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67 Although the terminology discussed here comes from Gee’s work, the general dynamics by which D/discourse is understood to operate fit well within the contours of linguistic anthropological approaches sketched by Ahearn (2001).
discourse.” Discourse is therefore inherently social; it is also incredibly powerful. When we name something using those words that others have used before us, we simultaneously describe it and call it into being. A palm-full of pills, for example, is one thing if those pills are “vitamins.” It is something altogether different if those pills are “antiretrovirals”—and the person who takes them is changed as well.

I agree with Gee’s (2005:1) notion that one of the primary purposes to which language is put is to “support the performance of social activities and social identities,” a human endeavor he memorably phrases as being, and being recognized as, “a particular kind of “who-doing-what”” (Gee 2005:23). What he means by this is that identity and performance are mutually constitutive, and acquire meaning within Discourses. That is, it is through our participation in particular Discourses (and Conversations) that we discover which kinds of people it is possible to be (recognized as being), as well as what to do to maximize our chances of being so recognized. As a corollary, we recognize other individuals as particular types of people doing recognizable things on the basis of Discourses as well. Already this dissertation has presented several identities through which we may observe this process. Prominent among these are “good/bad Brazilian woman,” and “Brazilian man” (“bad men” actually fall out of the masculine category altogether), but “parent,” “sexual-affective partner,” and “AIDS patient” also readily spring from the literature.

In order to make these “who-doing-whats” analytically visible, Gee recommends focusing on what he calls the “seven building tasks of language” (Gee 2005:11-13). These are listed and explained in Table 5.1 below. As is evident, language can accomplish many of these
tasks simultaneously; it can also do these things without the speaker’s conscious intention or even awareness. ⁶⁸

Table 5.1: 7 Building Tasks of Language

<table>
<thead>
<tr>
<th>Task Name</th>
<th>What to look for in a discourse analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Significance</td>
<td>How we use language to give things meaning, or keep them from being meaningful</td>
</tr>
<tr>
<td>Activities</td>
<td>How we use language to get recognized as doing certain things</td>
</tr>
<tr>
<td>Identities</td>
<td>How we use language to get recognized as being a particular type of person</td>
</tr>
<tr>
<td>Relationships</td>
<td>How we use language to construct particular qualities of ties between people</td>
</tr>
<tr>
<td>Politics</td>
<td>How we use language to convey and create perceptions of the “distribution of social goods”</td>
</tr>
<tr>
<td>Connections</td>
<td>How we use language to form or break connections between ideas, rendering some things “relevant” and others not</td>
</tr>
<tr>
<td>Sign Systems and Knowledge</td>
<td>How we use language to privilege particular ways of communicating over others (Standard English vs. AAVE, equations vs. words, or biomedical vs. popular explanations of disease, for example)</td>
</tr>
</tbody>
</table>

Each of the tasks listed above figures in my analysis (although they are infrequently made explicit), primarily as a way “into” the texts. I believe that much of the meaning in any text is only accessible if the notion of “context” employed in analysis—important for the derivation of meaning—is broad, and the acquaintance with that context is deep. As such, my analysis is based on ethnographically developed understandings of context, a design that is “appropriate when it is not only textual patterns but also their relationships with cultural constraints that are of interest” (Titscher et al. 2000:98). To perhaps a greater degree than emphasized by Gee, my conception of such “constraints” is firmly grounded in material factors. Lack of economic access to certain goods and experiences, for example, structures the kinds of activities, identities, and relationships available to speakers.

⁶⁸ In fact, many discourse analysts say speakers are frequently unaware of elements of their own production (on cultural models see Quinn 2005; D’Andrade 2005; see also Gee 2005:116).
In this analysis, I analyze respondents’ stories and words. Although this phrasing may seem pedantic, it is intentional. Stories, or narratives, are clearly made up of words, yet they are not reducible to words, and words are often significant at a sub-story level. Analysis of my respondents’ utterances—my attempt to "rescue the 'said'...from its perishing occasions and fix it in perusable terms (Geertz 1973:20)—accounts for these varied levels of meaning. Specifically, the couple sketches feature macro-levels of meaning: the dramatic events, the interpretations that recurred, the flux and foundation of daily life, compressed into one narrative arc. I focus on my participants’ stories because “they have something to say about what gives life meaning, what is inspiring in our lives, what is dangerous and worth taking risks for” (Garro and Mattingly 2000:11). In a separate chapter (see Chapter 6), I deal with considerations such as the framing of narratives (Agar 1996:32-33), what their contours reveal about the construction of HIV risk, and how particular linguistic details serve the ends of speakers.

Such forms of analysis are, of course, not without critics. Unni Wikan problematizes the prominence accorded illness narratives by social science researchers, asserting that though narratives may represent experience, how much and what kind of experience remains an open question. “People’s compelling concerns could be different; they need not be the illness, even when the illness looms large in a person’s life.” Illness narratives as presented in academic literature “are so often about ‘my illness and me’ as opposed to being integrated with ‘the ongoing story of [patients’] lives’” (Wikan 2000:218). Laurence J. Kirmayer takes issue with narrative analysis on a more fundamental level, arguing that “narratives are illusory, forcing the unruliness of lived experience into a coherent form with a clear beginning, middle, and end” (Garro and Mattingly 2000:267). He concludes that this confinement, as narratives “stabilize,” actually affects what can be remembered for incorporation into subsequent stories. Thus,
“narrative exerts effects that move backwards in time” (Kirmayer 2000:154). Garro and Mattingly (2000), and Luttrell would likely argue that even if that is so, since stories are ways people “define and defend their selves and identities” (cited in Quinn 2005:12), they have much to tell us, if we interpret them with caution. It is precisely for these reasons that an ethnographic approach is so important; the holism of ethnography becomes an essential resource for interpretation.

**Risk as Social Process: Selected Dynamics**

I have tried, for stylistic reasons, to minimize the insertion of overt analysis in the couple sketches. Nonetheless, the reader should be aware that the choice of which data to present already constitutes an analytical decision. This choice was based on two considerations: 1) What gives the best overall picture of this couple’s life? and 2) To the extent that overall trends within the data are present in a couple’s experience, how can they best be rendered? In order to prime the reader’s perception of these overall trends, prior to offering the sketches themselves, I briefly note which couples provide relevant cases to consider in relation to just four main areas: social class; gender, sexuality, and reproduction; serostatus; and stigma. Contrary to the expectations that initially structured this research, none of these factors neatly correlates with constructions of risk or patterns of HIV prevention.

**Class/Economic Situation**

Without exception, couples participating in this research commented on the challenge of meeting their financial obligations. However, this unanimity masks significant class-based differences. Some couples in the sample (i.e., Wilian and Pamela, Xavier and Juliana, and Renato and Milene) struggle to keep a roof over their heads, food on the table, and clothes on their bodies. Others (i.e., Iara and Jorge, Rita and Adriano) fight to maintain a lower middle-
class status. Bibiana and Felipe—notwithstanding Felipe’s assertion that the couple’s economic situation had been “tight” prior to Bibiana taking her most recent job—on the other hand, might spend as much on a single cut of beef to barbeque as other couples would on food for the entire week.

That being said, none of these couples seemed to be in danger of losing their home. As such, they were much better off than the AIDS patients featured in anthropological treatments of the commodification of HIV (see Chapter 3). As observed with reference to Abadía-Barrero’s work, which documented the advantages that accrued to HIV-positive children, vis-à-vis their uninfected counterparts, it is essential to be explicit about the basis from which the desirability of certain benefits is judged. Government assistance in the form of an R$800 monthly disability pension is likely to be evaluated differently, for instance, by those who struggle to obtain a job that pays one minimum salary and those who have held better-paid, more prestigious employment. In any exchange, what one has to lose—whether employment, material goods, or social status—is as important as what one stands to gain. Thus, difference in household-level political economy, both between other research samples and this one, and among this small group of couples, must not escape our notice. It is a fundamental element of the backdrop against which couples assess acceptable levels of risk and assign meaning in their lives.

Gender/Sex/Reproduction

As outlined in Chapter 3, in Brazil, hegemonic ideas about gender, sexuality (both in terms of particular practices and one’s orientation to and in those practices), and reproduction are multiply and densely articulated. In Gee’s parlance, they are part of the same Discourse. Hence, they are considered together here. Although notable trends emerged from the data, variation existed as well. Normative masculinity was on especially prominent display in most cases,
whether in the guise of sexual desire and experience (Jorge, Xavier, Adriano, and Wilian),
strength and independence (Adriano, Wilian, Felipe, and—in some senses—Jorge), or the
provider role (as foregrounded by Wilian, Renato, Xavier, as well as exemplified by Felipe).
Deviations from these standards often provoked commentary from the participants themselves.
The most notable “rich point” (Agar 2006:4) from these data was the almost total absence of
masculine expressions of distaste for condom use. Wilian, Felipe, and Jorge all came to accept
this practice and characterize it as necessary. Xavier and Renato had at their disposal other
explanations for their non-use of condoms (regardless of their underlying feelings); only
Adriano’s sexual nature as a man was explicitly identified as the reason for he and his partner’s
inconsistent HIV prevention practices.69

Female participants, too, both behaved and explained their behavior in terms of
normative femininity, although the coherence of dissent from this model may suggest a
countervailing Discourse. All of the women in the study assumed (and usually claimed to enjoy)
caretaking duties, whether these focused on their partner (for example, in Iara and especially
Juliana’s case), or also included children (Milene, Bibiana, Rita, and—as the archetypal
example—Pamela). They were also fairly united in their assessment of male nature (disinclined
to monogamy, in need of care and limits, and emotionally or psychologically weaker than
women).

With regard to sex, however, there was considerable diversity. The trope and value of
feminine sexual inexperience was both invoked (by Rita and Pamela) and contested (by Iara,
Milene, and Bibiana). In addition, at some point in these stories Iara, Juliana, and Milene are all
identified as agents in determining how and whether condoms will be used with their partners, a

69 And it should be noted that even he claimed that, if a man concentrated on his partner and the pleasure
inherent in sexual intercourse, one could forget one was even using a condom (interview, 10 December
2009).
finding the bulk of the literature on this topic would not have predicted. On the other hand, as in Persson and Richards’s (2008) analysis of a female informant’s decisions involving condom use in a serodiscordant relationship (see Chapter 3), the complexity of these stories requires significant effort to unpack.

The importance of reproduction as a performative aspect of both femininity and masculinity, as well as its role in solidifying heterosexual conjugal relationships in Brazil, also was explored in Chapter 3. Among this sample, childbearing/family formation was relevant to varying degrees and expressed in several ways. For some couples, (Xavier and Juliana, Wilian and Pamela), biological factors eliminated natural conception as an option. In others (Iara and Jorge, and Bibiana and Felipe), the importance of reproduction within heterosexual conjugal context is marked through its absence, and sadness around that absence. Nonetheless, adoption is practiced or mentioned as a possibility by two of these four couples, suggesting other ways to accommodate these norms. Finally, in two couples, conception and childbearing were either dreams considered possible to achieve, or plans coming to fruition. Rita and Adriano welcomed their first child—a son—into the world over the course of this research. Renato and Milene, for their part, both expressed their desire to conceive together, and were taking steps to ascertain the possibility of doing so.

**Serostatus: Contingent Meanings**

The significance with which reproduction is invested may be at least partially a manifestation of what seems to be a preoccupation with “normality,” especially as given voice by those who carry the virus (e.g., see statements made by Iara, Renato, Bibiana, and Felipe). Even when participants do not use this word, they often evoke a similar idea. Rita, for example, in explaining why she doesn’t find Adriano’s jokes about HIV very funny, talks about what
she’s gone through “to get my life back to what it was before [my diagnosis].” While more systematic analysis is accorded these expressions later (see Chapter 6), at this point I merely wish to bring such utterances to the reader’s attention, since they constitute obvious attempts to renegotiate the meaning of seropositivity. I say “renegotiate” because, although HIV can be portrayed as many things in mainstream Brazilian Conversations about the virus, “normal” is not among them.

Other ways this contestation occurred was through active dissent of stereotypes and “misconceptions,” especially about modes of transmission and the idea that HIV is a “death sentence” (e.g., statements by Xavier and Juliana, Rita, Jorge, Pamela, and Felipe). Silence was also frequently employed. Some couples (Xavier and Juliana, Wílian and Pamela) when asked about their lives, simply did not spontaneously talk much about HIV. But the contingency of meanings associated with HIV and the risk of transmission was evident within couples as well. Change over time, as well as in response to particular life events, produced radically different evaluations of the virus from Renato, who discussed his life as a seropositive person as being both “normal” and a “prison without bars” (analogous dynamics are detectable for Iara, Xavier, Rita, Bibiana, and Felipe). Also notable is the attribution of positive characteristics to seropositivity by Milene.

Although, as documented in Chapter 3, many academic treatments of HIV/AIDS would not take such multiple meanings of serostatus seriously (rather, most typically, considering them forms of denial or misinformation), a further critical step must be taken. This means embracing the possibility that serodiscordance is not necessarily experienced as “difference” by the members of these couples. In this vein, Persson’s (2008) notion of “sero-sharing,” a mode of relating to HIV within serodiscordant couples that emphasizes how both partners are affected by
the virus, is especially useful. In the sketches of Iara and Jorge, Wilian and Patricia, and Bibiana and Felipe, we find clear cases of this dynamic; for the three other couples, various interpretations could be advanced and justified. Of note is that in this sample, “sero-sharing” was frequently enacted around medication, and elicited a variety of emotional responses, from ranging from appreciation to irritation. Finally, we must be attentive to instances that suggest positive/negative serostatus may not be the most meaningful distinction employed by a speaker—even when the conversation is about HIV and risk. Adriano’s attribution of non-transmission to internal, unseen differences in immune response among the supposedly monolithic group of “seronegative people” is a stellar example in this regard.

**Stigma**

Finally, I wish to call readers’ attention to HIV-related stigma in the following sketches. Participants in this research demonstrated high levels of anxiety regarding stigma and its effects; this was one of the most consistent patterns identified in the data overall. Notwithstanding their attempts to renegotiate the meaning of seropositivity mentioned above, perceptions of the prevalence of stigma impacted not just decisions regarding disclosure of serostatus and/or serodiscordance, but social interactions more generally in all couples. In most cases, practices of selective disclosure, or “information management” (Goffman 1963) were in effect, with only the couples’ closest friends and family being informed. Sometimes, not even the seronegative member’s immediate family was informed (as in the case of Felipe and Adriano), or was told only belatedly (as happened with Juliana’s children). This pattern occurs among a sample—admittedly small—in which most of the seropositive members are in good health. Their ARV regimens have produced stable (or rising) CD4 counts and undetectable viral loads. None of them are readily identifiable (in accordance with Brazilian cultural logics about physical
appearance and health) as AIDS patients. As such, they can be expected to have personally suffered from stigma less frequently than those who manifest the visible marks of AIDS. And yet, socioculturally speaking, other people’s notions of “contagion” remain a major concern in their lives.

Iara & Jorge

Iara and Jorge live together in a house one stop from the end of the bus line that serves their neighborhood, one of the southernmost of Porto Alegre proper. At the time of their participation in this study, they had been together six years, although they were not legally married. They had no children together and neither had children from previous relationships. As Iara had been diagnosed with AIDS in January of 2009, only eight months before I met the couple, their relationship was well-established prior to discovering her seropositivity. Jorge was an only child and his father had passed away; both of Iara’s parents were still living and she had several siblings and a collection of nieces and nephews. Though she had become closer to her family since her diagnosis, historically this was not characteristic of her relationship with them. She claimed to have always been the “black sheep,” due to her extremely independent nature.

Iara was 44 years old, had completed high school, and held many jobs in her life. Most recently, she had been fired from a State government office, ostensibly as a result of the absenteeism provoked by side effects of her ARV regimen. She had documentation which should have exculpated her for these medically-necessary absences, but she believed changes in her physical appearance, coupled with so many atestados, led her superiors to suspect her HIV status. Indeed, throughout the time I visited her, her health was somewhat precarious. This was not surprising, as her CD4 count hovered between 150 and 250. In comparison with her condition at the time of her diagnosis, however, this was a dramatic improvement, achieved
through ARVs. She had begun taking medication at the hospital where she was diagnosed; subsequently, though she continued to receive follow-up care at the hospital, she filled her prescription at a State-administered HIV/AIDS treatment center. An adverse reaction prompted a change in drug regimen in May of 2009. Afterwards, several factors led her to transfer her treatment and prescriptions to the municipal clinic. I met her on the very first day of my observations there, which was also her first day as a patient, and the first time she met her new doctor.

Iara is a robustly-framed woman, tall by Brazilian standards and overweight. Her thick, curly hair was cut fairly close to her head and dyed a reddish-brown; she looked as though she would tan easily and could be identified as either branca (White) or parda (mixed), depending on the social situation. In her interactions, if not her larger physical movements, she gives a distinct impression of quickness—her eyes are quick to glance, twinkle, and blaze; she speaks quickly; her mind seems to be constantly in motion. I found her assertive, friendly, talkative, with an easy laugh and a way of telling stories that made one feel as if great hilarious secrets were being shared. She also frequently demonstrated her concern for others’ wellbeing. For example, the day we met, I was an obviously nervous anomaly in the clinic waiting room, and I think she talked to me as much to make me feel better as because she was curious about me. She kept up a rapid-fire stream of conversation for nearly an hour before they called her for her appointment and she returned afterward to encourage me to call her about the study and to wish me good luck.

It would be inaccurate, however, to paint a picture of Iara as saintly; she could be quick-tempered and jealous. Very much a member of the material world, she enjoyed cooking and food. She relished recounting past sexual encounters and her humor was often quite bawdy. In
addition, money and small luxuries were objects of explicit pursuit for her. The stories she told about her life often included subplots in which her charm was skillfully deployed for her own, or a friend or family member’s, benefit. She was, however, quick to differentiate between bending rules to this end and breaking them, and emphasized that she only sought these gains for herself and others from individuals or organizations with sufficient means to provide such advantages. One could not but be impressed with her ability to “size up” a situation, accounting for the logistics, social dynamics, and resources potentially at play.

Iara is a mãe de santo, a priestess/practitioner of the Afro-Brazilian syncretic religion of Candomblé. Thus, in addition to her formal participation in the education system and labor market, she had also spent years in apprenticeship and practice of what she always called a religião, or “the religion.” This was important not only because it offered a way for Iara to deal with her own experience of ill health and seropositivity, but also because helping seropositive individuals in her capacity as mãe de santo had forced her to confront several popular misconceptions about HIV even prior to her diagnosis. In addition, most of those who came to her for succor compensated her in some way—although during the period of this research such remuneration was not steady or sufficient to cover the couple’s living expenses.

Jorge was 30 years old, with an athletic build that was perhaps just beginning to show the results of a slowing metabolism. On the tall side of medium height, his tightly-curled black hair was shaved close to his head; his skin was a rich, warm brown. He had worked as a security guard, including for a large transportation company in downtown Porto Alegre, but when I met him he was out of work and receiving unemployment insurance. He liked his profession and was actively seeking another job in the same area. His social networking page featured several photos of him with co-workers, posing with their handguns. As time went on and he had
difficulty finding work, he was frequently to be found in the bedroom watching TV when I
arrived, usually dressed in a T-shirt and shorts. From time to time he would leave the house to
smoke a cigarette; Iara’s doctors had said the second-hand smoke would aggravate the
respiratory illnesses she’d been prone to since her HIV diagnosis.

Jorge was quiet and placid in my presence, and although these qualities may have been
accentuated by the circumstances of our interaction and the challenging time he was going
through, they seemed nonetheless to be part of his general disposition. This contrasted with
stories about rare and usually alcohol-related storms of expressiveness; Jorge seemed to be able
to tolerate a lot but once he reached a certain point, he boiled over. I never saw one of these
episodes nor heard about one happening during the period that I spent time with the couple, and
Iara contrasted Jorge’s forbearance with her own quick-to-anger tendencies. He had completed
“primeiro grau,” approximately 8th grade, but, despite this relative lack of formal education,
possessed a surprising command of written English (he refused to speak it with me, however).
After I discovered this, I usually brought him worksheets or activities that I had created for my
English students, which he said he enjoyed. He was curious about life in the U.S. and
occasionally would ask me questions. These conversations often got derailed, however. Since
he was much less extroverted than Iara, she usually ended up doing the talking when the three of
us were together.

Much of the talk was about Iara’s health and often ran back to the time of her HIV
diagnosis. It was both the end of a long medical sojourn and the beginning of a new phase of her
life. Iara had been ill toward the end of 2008 with various symptoms, including a skin rash,
vomiting and a cough. She’d gone to a neighborhood health post (Unidade Básica de Saúde or
UBS) for diagnosis and treatment, but the doctor there had told her these problems were just a
“coisa de idade,” or part of getting older, despite the abnormal results of the bloodwork he ordered. Time went on and she began to have difficulty breathing. She was referred to a specialist who, after examining her and an X-ray of her lungs (most likely to rule out tuberculosis), declared that she had some kind of “reflux.” But she didn’t respond to treatment for that condition and another doctor disagreed with the diagnosis, deciding instead that she suffered from a sinus infection. She was not getting better. She said that all of her normal appetites had evaporated; she had no desire for sex and “couldn’t even look at food.” By the time she went to spend Christmas Eve with her natal family, she had lost 25 kilograms (55 pounds) and her nieces refused to hug her, saying “No! I’ll get that disease!” If anyone had known what Iara’s underlying illness was, they might have known that it was not transmissible through hugging, but since no one knew what she had, they kept their distance.

Her most acute suffering, however, was respiratory, and that night she had so much difficulty breathing she ended up in the ED at one of the city’s well-regarded hospitals. After her airways were opened, she was diagnosed with serious pneumonia and admitted to the hospital. Exactly when those responsible for her treatment became aware of her HIV status isn’t known, but she noted that the nurses did not discuss her diagnosis in the same way they did the other patients’. Most of the other patients on her ward were older women with cancer; between 24 December 2008 and 16 January 2009 (the period of her hospitalization), she saw 10 of them die. Iara wondered what diagnosis could be “so much worse than cancer” that the nurses wouldn’t discuss it, and began to despair of ever leaving the hospital. She worried that, if she did get to go home, she would need an oxygen tank for the rest of her life and wracked her brain for ways she might be able to afford it.
These were difficult days for Iara and Jorge. He spent long hours with her at the hospital, but also was working full time. Iara talks about crying herself to sleep on his chest. After one such visit he returned to his mother’s house asking, “Could it be that she’s really going to get out of there?” Because of her hospitalization, Iara did not go through the group-based, pre- and post-test counseling sessions common in Porto Alegre’s public HIV testing centers. She received her diagnosis on 8 January 2009, and although her outlook had been bleak prior to that point, she told me, at the couple’s joint interview, “When that news came, you know, that’s when I lost it. I went craaaaaaaazyyyyy... I wanted to tear myself apart... then, later, things calmed down, you know? But it’s cruel—right, Jorge? The first days—dang!”

After receiving the results, she had telephoned her partner in tears, asking, “What now?” Jorge’s tone, as he answers my questions about this, is matter-of-fact, but he laughs nervously after giving a bare-bones account and I have to press him to elaborate. He says his goal in responding to Iara’s question was to avoid making things worse for her, and his voice gathers strength as he describes her emotional fragility at the time, the stress caused by being in the hospital for so long, separated from her daily routine and family, continually being stuck with needles. His response to her was characteristically masculine in its stoicism and practicality: “Afterwards, we’ll deal with it; the first thing is to take care to get you out of [the hospital].”

She did, of course, get out of the hospital, but the story of her time there and the fear and sadness it provoked in her were themes Iara reiterated in almost every interview. She plainly stated from the beginning that she considered death a distinct possibility, and both Iara and Jorge’s narratives, as well as her CD4 count—only 34—at the time of her diagnosis, suggest that she had every reason to do so. At an interview three months after I’d met her, I asked if she thought her relationship with Jorge would be different if there were no treatment for HIV. She
did not hesitate in responding affirmatively: “Because I would know that I’d go more quickly. There wouldn’t be much survival time.”

By the time she herself was diagnosed with HIV, however, Iara was well aware of the power of ARVs to extend life. A sequence of examples in fact figured prominently in at least three different interviews I did with her, and was additionally tied to her practice as a mãe de santo, an extremely meaningful aspect of her identity. In each instance, which occurred between 4 and 8 years prior to her telling these stories, an individual contacted her for assistance in determining the cause of ill health—either her/his own or that of a family member. All of the clients were men in fairly dire straits whose cases had stumped their doctors—despite their clinical presentations of rapid weight loss, respiratory infections, and skin conditions being textbook examples of AIDS. Iara’s response in each case was to jogar búzios, a divinatory practice in which the orixás, or saints, are consulted about human affairs. A set of cowrie shells is thrown, somewhat like dice, and, from the resulting position and pattern of the shells, answers to the questions asked before the toss are decoded. Iara did not claim to have divined the exact cause of any client’s health issues, merely that the person was suffering from a very serious disease. In one case, she predicted that the etiology of disease would become known very soon (this client was diagnosed with AIDS two days later).

These stories had other elements in common as well. Iara had given all of these men the same advice: that she would see to the “parte astral” (supernatural part), but, “You have to do medical treatment, as the doctor prescribes it.” Significantly, in every case, the client recovered sufficiently to regain the weight he had lost and continue with his previous activities. This was phrased as “voltou normal” (he returned to normal) or “tu não diz que ele tem” (you wouldn’t know he had [HIV]). One of the three men does not, she claims, take ARVs; his mother bought
a book about homeopathic nutrition and he eats special combinations of foods and very healthily on the whole.\textsuperscript{70} The upshot of these stories is that Iara has seen, several times over, that AIDS is not a death sentence. In addition, \textit{a religião} is consistently viewed as offering her clients an avenue through which to take positive action; these men became agents in pursuit of their own health, even when doctors were temporarily confounded. It bears mentioning that this agency was usually in addition to physicians’ orders, although in one case it was implicitly positioned as demurring from them.

Iara herself also exercised health-related agency, both through \textit{a religião} and more mundane practices. From the time of our first meetings at her home (in September of 2009) she was involved in planning a party to be thrown on Children’s Day (12 October in Brazil) as an offering to Xangô, her \textit{orixá}, to give thanks for and ask for continuation of her recovery. This party was vitally important to her, and an enormous undertaking. The guest list was to include every child in her neighborhood, as well as a circle of her close friends and family. As prescribed by \textit{a religião}, Iara would provide at least a special soup, ritually-sacrificed chickens, several different kinds of cakes, bottles upon bottles of soft drinks, and bags of candy. In addition, she needed special clothes for the event, and she felt compelled to also hire a drummer. Receiving her promised financial support from the government was necessary in order to pay for all of this, and she anxiously awaited its arrival, wondering if it would come in time. It did not. She was nonetheless able to have the party about a month late, due to receiving a smaller-than-anticipated disbursement from the government and contributions to the party from various members of her social circle (including myself).

\textsuperscript{70} Taking this assertion at face value, and even if one believes that improved nutrition alone could not produce this result, we should recognize that in none of these narratives did Iara mention the client’s immunological indicators, like CD4 count or viral load, so it is possible that ARVs might not have even been indicated in this case.
Iara’s painstaking and detailed fulfillment of the religion’s dictates for the party indicates her diligence in dealing with the “parte astral” (supernatural part) of her health, much as she’d counseled her clients. Her personal practice when it came to her pharmaceutical regimen, however, deviated from the way she had exhorted them to behave. The “coquetel” (the Brazilians, just like their North American counterparts, call HIV combination therapy the “cocktail”) she’d been taking since May of 2009 consisted of three drugs, two of which she took once daily and one that she took every 12 hours. She also had a current prescription for Bactrin, an antibiotic intended to defend against opportunistic infections, since her CD4 count was still considered quite low. She refused to use the antibiotic, on the grounds that it made her horribly nauseous.

In addition, adhering to her ARV dosing schedule was a struggle. She made no attempt to hide this from me, saying, “Sometimes, I don’t feel like taking one more thing. I forget—you know, I think I’m normal. And then it happens one day that—gasp! I didn’t take my medicine this morning. Then I take them all, you know?” I witnessed her taking her ARVs on at least three separate occasions—but since I usually arrived to eat lunch with the couple, this meant she was taking her “morning” dose between noon and 1 pm. She explained that many times it was Jorge who reminded her to take her medicine at night, a clear example of sero-sharing. I asked her, when we were alone, how that made her feel. She replied, “It’s good because it makes you feel like someone…is taking care of you….When I’m in bed, you know?…Sometimes I forget and he brings the water, medicine, everything. And he stands there until I take it (laughs).”

I asked her if she worried about skipping doses of prescribed medicine or taking them late. She denied this, and cited her increasing CD4 count as evidence that she was not “em falha” (in treatment failure). She continued the conversation by linking her recovery to the
amount of weight she’d gained back. In March 2009 she had weighed 87 kilograms, in November of that year she weighed 125, something for which she said Jorge had chided her. In addition, the medicine she’d taken to treat her pneumonia while she was in the hospital had made her teeth very weak and many of them had broken. She sighed that she found this distressing; it made her not want to smile. But fixing the problem would be expensive—over R$ 1000. With Jorge out of work, her benefits uncertain, and the party to pay for, it wasn’t something they could afford at the time. Overall, aesthetic concerns seemed to preoccupy her more than medicine, and she seemed to conceptualize her adherence to her medication as “good enough.”

This is not to label Iara as “noncompliant,” however. Even if one were interested in applying such labels, an important observation that can be made on the basis of Iara’s case is that “compliance” is a multifaceted concept; it is not necessarily an all-or-nothing behavior. For while Iara omitted her prophylactic antibiotic, she at least claimed an intention to take her ARVs as prescribed, and, in yet another important domain, she was a model patient, even contradicting conventional (academic) wisdom regarding the parameters under which such practice might be expected. That domain is condom use.

Iara positively reveled in telling the story of Jorge’s initial resistance to condom use. She said that when she finally came home from the hospital and they had to deal with this issue, Jorge had argued that he didn’t want to change their sexual practice (they had dispensed with condom use very shortly after getting together). He wanted to “be in the same boat she was,” and tried several times to convince her that condoms weren’t necessary. Thus far, the story presents the contours of other cases found in the literature: male refusal of condoms, risk-taking by seronegative partners, etc. But Iara, upending traditional notions of femininity on one level, insisted. “Are you crazy?! Go shoot yourself in the head then,” was her response. She had
argued that Jorge’s logic was short-sighted—what would happen when they both fell ill? Her partner, during their joint interview, agreed that foregoing condom use would have been a mistake. In his individual interview, he characterized his original rejection of condoms as misguided, going so far as to discursively disown the impulse when he said, “It wasn’t me—I was out of my head.” Having interpreted his statement literally, I didn’t understand what he meant and had to ask for clarification. “I’d been drinking,” he replied, acknowledging that he had engaged in bouts of heavy alcohol use after Iara’s diagnosis.

This was one of the pieces of evidence that Iara usually cited for her assertion that, as she explained on at least three occasions, Jorge did not have the “emotional structure” to deal with seropositivity. She claimed that she had to fight to establish condom use after her diagnosis for his protection. She said it was one thing for him to suspect that he had HIV (and he hadn’t handled that so impressively), but it would have been quite another for him to actually know he was infected. Although when Jorge discussed this period with me he implied that he would have eventually accepted the necessity of condom use on his own, Iara’s narratives always foregrounded her agency, her decision, as the catalyst for practices that would keep Jorge safe. Both of them claimed that, after her diagnosis, they never had sexual contact without a condom and did not foresee any reason to alter this practice. It should be noted that in this “caretaking” sense, Iara’s insistence on condom use fits in with traditional notions of femininity.

Another narrative in which Jorge was painted as in need of guidance and care also came from the time period immediately after Iara’s diagnosis. She frequently teased him in my presence about how strongly he had resisted getting tested for HIV, saying he only gave in when one of the hospital doctors finally cornered him in the hall about it. Although this originally led me to assume that Jorge had been tested before Iara was released, he told me later he had been
tested at a well-known, state-administered testing and treatment facility in early March of 2009—two months after she went home. By the time of the individual interview I did with him, I had heard parts of this story twice, so I asked him to tell me about getting tested. He insisted that he knew he had to get tested and he wasn’t refusing to do so, he just didn’t want to do it at that time. He first, almost jokingly, mentioned his fear of needles, but then continued, saying he’d assumed that he was infected—in fact, he didn’t see any way for it to be otherwise, after four or five years of exposure: “Since I was already resigned to [the idea of being seropositive], as though I already had it, it was just a question of taking the medicine and getting on with life. [I thought] There’s no way to go back, no way to go back now.” He claims merely to have wanted some time to adjust to Iara’s diagnosis before receiving his own.

For her part, Iara agreed with Jorge’s assessment that there was every reason to suppose he carried the virus (and in that case it would have been impossible to tell which of them had given it to the other), but she claims to have known, although she couldn’t say how, that Jorge was seronegative. She interpreted this as a kind of second chance for him, which seemed to cement her resolve to avoid transmission. She explicitly constructed maintaining his seronegative status as the concurrent maintenance of his acceptability as a sexual and affective partner for HIV-negative women. In the first formal interview I conducted at the couple’s house, she said she sometimes thought she should leave Jorge, for his own good: “There are times I think that he shouldn’t be with me, you know, that he should go live his own life, get back to having a normal life. Sometimes I think he’s with me because he feels sorry for me.” Demonstrating her profound ambivalence about this issue, in the next breath she offered a contradictory opinion, saying, “[Then] there are times that I think, ‘No, if he didn’t like me, he wouldn’t be with me,’ you know? Pity—this thing of, ‘Oh, how sad!’—that doesn’t exist.”
Iara and Jorge’s relationship was sometimes difficult. Aside from disagreements over budgeting (e.g., Iara’s irritation over her perception that whenever Jorge had money, he spent too much on beer and cigarettes) and jealousy (Jorge implied that he found Iara’s “outbursts” about other women trying), Iara noted that there were times she simply could not subordinate her inclination toward independence, and that Jorge also acted this way: “We don’t have an attitude like we’re a couple, get it?...But sometimes it’s unintentional, you know? Because I always had to handle things myself. Since I was young....I never waited on people. I always had to go out and get everything. So now—not that that has changed, ok? But it’s that now I share my life with someone.”

During the third month of her participation in the study, Iara confided to me how seriously she had wondered, subsequent to her diagnosis with AIDS, how much longer that would be the case. Doubts about the future of her relationship with Jorge were portrayed, however, as stemming from what she considered the utter comprehensibility of his potential decision to leave her. As she explained, “I thought he would want a different life. [But] nothing changed. And that surprises me, you know? Because at his age, with everything he has in front of him, being younger and me having these problems, he gives up many things to stay with me.”

Asking or allowing Jorge to give up these things was an idea that Iara never seemed able to totally accept. Although it was clear she fervently wished for their relationship to continue, her conception of the roles and responsibilities of intimate partnership—and her conviction that she could no longer fulfill these expectations—seemed to goad her into saying things that were ultimately upsetting to both of them. For instance, she recounted a time she’d suggested it might be better for him to find another woman. Jorge had responded, “Why are you saying that?” and her reported reply initiated a rapid back and forth: “So you can have a normal life.” “But my life
with you is normal.” “A woman who wants kids, a family.” “But I don’t want that; I want to be with you.”

As is evident, this phrase, “a normal life,” which recurs throughout Iara’s interviews, is intended to convey the idea of living life fully, in accordance with normative dictates about relationships. Not solely a reference to their sex life, which had diminished both in frequency and in ardor (other segments, not reported here, speak to that issue), it also encompasses the idea of having a child. Both Iara and Jorge said that they had previously talked about having a child together. Jorge explained that this couldn’t be characterized as any sort of definite “plan,” just that it had been a possibility, something they had thought about for the future. He spoke of the availability of treatment to prevent vertical transmission as well as the possibility of adoption, but stressed that the couple’s finances and Iara’s rather precarious health meant that the current moment was not a propitious one for them to become parents. According to Iara, however, any idea of children “foi de uma vez” (was gone instantly) after her diagnosis. For her, the subject seemed simply closed.

In addition to Iara’s health, the other major topic of conversation when I asked Iara and Jorge about their lives was finances and, particularly, “benefícios” (literally, “benefits,” but used to indicate anything guaranteed to a person by Brazil’s social welfare programs: unemployment, disability, retirement, and other entitlements). Although HIV/AIDS-related benefits were discussed in the Setting chapter, it’s important to know that, over the course of the AIDS epidemic, what an AIDS patient might expect from the government has changed dramatically. In the early years of the epidemic, when survival times were short, the “normal” course of events for individuals diagnosed with AIDS was to be quickly granted a retirement pension. Indeed, several of the “old guard” activists that I met in Porto Alegre had been diagnosed and “retired”
years previously and, unlike unlucky tens of thousands before them, they lived to become evidence of the astounding effectiveness of ARV treatment. Unable to accept formal employment, which would permanently disqualify them from receiving retirement benefits from the state, they essentially work as full-time volunteers. This, of course, was not a sustainable situation for the Brazilian state. As the effects of ARV treatment began to manifest, it became progressively more difficult to win definitive retirement on the basis of an AIDS diagnosis alone. Instead, medical documentation of special circumstances or disabilities, gathered from doctors and submitted at multiple hearings, was necessary to be awarded such a benefit. On the other hand, in cognizance of the deteriorated physical condition that many Brazilians reach before being diagnosed with AIDS, it is common for these individuals to receive auxílio doença, or temporary disability. As noted previously, these cash payments are not just for AIDS patients, but for any individual who has previously contributed to Brazil’s social security system, and, for various health-related reasons, is unable to work. Auxílio doença however, requires frequent re-certification; it is not intended to be permanent.

Throughout most of the period I spent time with her, Iara received auxílio doença. She was the only seropositive participant in my study receiving this type of assistance (four of the others were working; one was retired through disability), although one of the seronegative participants was in the process of appealing the rejection of her application for this benefit. Iara seemed always to be not-quite-over a respiratory infection, suffered from swelling that may have been a side effect of her ARVs, and tired easily. She acknowledged that these problems were not totally debilitating, but she did not feel well. She was pessimistic about finding employment, partially because of her experience being fired from her last job and partially because she felt she lacked the vigor and endurance she had brought to her work previously.
Aware that her temporary disability payments wouldn’t last, she was actively engaged in pursuing a more permanent basis for receiving assistance. This came as quite a surprise to me, since when I had asked her about benefícios, on the first day we met, she had responded, “Tudo que vem é lucro,” which literally means, “Everything that comes is profit.” My interpretation of her statement led me to believe that she would accept what came her way, but wasn’t too committed to the idea of obtaining something from her diagnosis. But she was clearly working hard, not just to get something, but to get the best deal possible. Her efforts on this front were a significant focus in many of our interactions, and are detailed in Chapter 7, which deals explicitly with commodification and citizenship. Here, I want to briefly explore Iara’s concern with HIV-related stigma, as well as her attempts to integrate seropositivity into her identity.

Experiences and fear of stigma were woven throughout Iara’s narratives, and seemed to come from a bewildering variety of sources. She had not even been released from the hospital before having to confront such issues. For example, at one point the staff suggested that a family member or friend be with Iara at all times; she was so weak that she had fallen from her bed on several occasions and had not been able to raise herself. Several of her friends offered to take a shift, including three from her place of employment. Of the three, only one, who was a nurse, discovered Iara’s diagnosis. The other two subsequently went to ask, “So what is it that Iara has anyway? Could it be that she has HIV, that she got AIDS (this last word said dismissively, with disgust)?” The supervisor at work also pressured this friend for Iara’s diagnosis—which she revealed to no one. She did, however, tell Iara about what had transpired. In concluding these stories, Iara remarked to me, “People just have no discretion when they want to find out something, something that’s private about you.”
Upon returning to work, Iara said she began to see that stigma shaped people’s speech and actions in ways that went beyond HIV, but that were hurtful to her because she interpreted them as parallel structures. She tells of waiting to go into the office one day, shortly after the H1N1 outbreak (in which infection for many people in Rio Grande do Sul was traced to exposure while travelling to, or contact with those from, Argentina), when a co-worker remarked, “‘I’m so pissed at the Argentinians.’ ‘Why?’ [Iara had asked.] ‘Because those bastards brought that disease to us.’ I said, ‘That’s your ignorance; no one chooses to get sick.’...She was talking that nonsense. But I didn’t say that because of the flu; I said it because of [my situation]! You know? Because I saw that was a person who discriminates.”

Even within their families, Iara and Jorge were cautious about disclosing their serodiscordance. During the couple’s joint interview, Jorge explained that they had told those they were closest to, partly because, given their visits during Iara’s hospitalization, it would have been impossible to keep it from them anyway. Iara agreed. They both seemed to consider this an important and delicate matter:

Jorge: We start by saying, ‘Look, don’t tell anyone,’ and everything...So, moms, sisters, that kind of thing. In my case, only my mom knows.
Shana: And is that because...she’s the only one that “needs” to know? Or because you [indicating both members of the couples] don’t want the others to know, or...?
J: Yeah…it’s more because of the stigma, right? There are a lot of people that, if they find out, they won’t want to come here, they won’t want to maintain contact, you know?

Iara emphasized that, even knowing that Jorge was not infected, many people would treat him differently because of her serostatus, something she wanted to avoid. Over the time I knew her, Iara’s stance on disclosure seemed to moderate slightly; she sometimes chose to reveal her serostatus, particularly when she thought the knowledge might help someone. But it was never a decision she made lightly.
Such changes were perhaps to be expected; since Iara’s diagnosis was so recent, she was actively processing what her new serostatus meant in the context of her life. Her emotions varied; some days I found her defiant, others despondent. At the couple’s joint interview, in September, I’d asked them if they’d learned a lot about HIV—a question I meant in a biomedical vein. Iara, however, took her answer in a more existential direction, saying, “Living with the disease, each day you learn something different. But, oh, I don’t know, it’s strange; there are times—like I told you—that you forget you have it, but other days you remember every minute.” This consciousness seemed to weigh on her nearly as heavily as the lack of sexual desire and physical pain she suffers, both of which she attributed to the ARVs that she knows are saving her life. Ambivalence and contradiction seemed the rule.

Iara’s health did improve while I knew her, albeit rather slowly. She also (as documented in Chapter 7) felt the couple’s economic situation looked more encouraging as the months passed. Both of these considerations seemed to lighten her spirits. Jorge noted that over the course of 2009, she was “returning to normal,” and, while the restoration of her appearance had occurred mostly prior to my meeting her, I appreciated his observation, since I found her stubborn, mischievous, and independent streak more and more consistently expressed. At one of her last interviews, Iara reflected on what she saw as her place in the world, as a person living with HIV/AIDS:

Even with these problems, I’m not a victim. I’m not “less” than anyone. I don’t accept it when people say things like, “Oh, those miserable unfortunates.” They don’t have any reason to say that pile of B.S. You know, sometimes I speak up [about her serostatus]. And if they don’t like it, tough. You know? [As though talking to such a person:] “Oh, you’re afraid? That’s your bad luck...I’m the same person. It’s just this thing in my blood that changed....I’m the same.
Xavier & Juliana

The same day that I met Iara, I also met Xavier. He was affable, curious and loquacious. Xavier lived with his partner of nearly 8 years, Juliana, a woman 12 years his senior, in a neighborhood immediately adjacent to the clinic. They were not legally married and had no children together, although each had several children from previous relationships. Unlike Iara and Jorge, Xavier and Juliana had been cognizant of their HIV serodiscordance from the beginning of their relationship; Xavier had been diagnosed 14 years before I met him.

Xavier was 45 years old at the time he was recruited into the study. He was Afro-Brazilian, of medium height and somewhat portly, with pronounced difficulty walking. He cut quite a memorable figure—almost genteel—with his cane and his fedora, greeting everyone he knew as he strolled through the neighborhood. And stroll he did—seemingly to anywhere he could find conversation partners. He often ventured up to the health center just to chat with the security guards. Xavier loved to talk; when he, Juliana and I were together, the conversation usually consisted of him telling stories in response to my questions, or irrepressibly following a thread of his own. Juliana and I laughed, or I did; it sometimes seemed she tired of his monologues and would sit looking off in another direction or watching the muted TV in their living room.

Many of these were stories from what Xavier seemed to hark back to as his “glory days,” when life—to hear him tell it—revolved around drinking, using various illegal drugs, and playing the cavaquinho (a stringed instrument much like a small guitar, introduced in Brazil by the Portuguese) with friends. He often followed such tales with a story of one of the many relapses in his struggle to get and stay sober. This dialectic seemed to me the current “ground zero” of Xavier’s identity. Indeed, within ten minutes of my meeting him, he’d identified
himself as an “ex-dependente químico,” a former addict. It was clear that, for all the fun he’d relished, he also saw himself as having paid a price, in “descuidos” (essentially, slip-ups) that led to his infection not only with HIV, but also Hepatitis C. Just a few months before I met him, he had completed a nine-month course of treatment for the latter. Although this was available through SUS, the regimen was costly; according to Xavier’s doctor, generally only those with severe liver damage were approved to receive it. The treatment was considered potentially arduous for patients, and it was so for Xavier. Juliana concurred that the last three months he was so irritable it was almost intolerable to live with him. Yet the first round hadn’t worked. His doctor recommended that they pursue a second round; the only other option was a liver transplant.

As grave as that situation was, Xavier elected to postpone the treatment, in order to address what he considered his most pressing health concern: his lack of mobility and the pain associated with it. He needed, he told me, a double hip replacement, and had been on a SUS waiting list for years. The first surgery had finally been scheduled for October; I visited him in the hospital while he was recovering. This debilitating condition, though aggravated by an accident, was really, he said, the result of overuse from capoeira, a Brazilian martial art, which he had practiced from the age of nine. His step-father had been a mestre (master), a status Xavier himself claimed to have achieved by his teens. He became a teacher in his own right, which led to travel throughout Brazil and living in the states of São Paulo, Bahia, and Minas Gerais for a short time. He often referenced these experiences in a very general way, as evidence of our presumed affinity. Although he acknowledged his relative lack of formal education, his time of “vivendo fora, que nem tu” (living outside [of one’s birth place], just like you) was used to prove that he’d been in “the school of life,” and thus was wise.
In fact, Xavier several times discursively positioned me, when we were alone, as being very much in need of his wisdom and guidance. His construction of this need was both troubling and theoretically illustrative. First, to the extent that it resonated with the Brazilian gendered (and sexual) norms of male experience/female inexperience, it constituted a backdrop to our interactions that was difficult for me to manage in the context of a research-based relationship. In isolation, this would not have been so problematic, but it figured into an unmistakable pattern of behavior (see below). This pattern, of course, was also ethnographically interesting as an example of the continuation of traditional forms of Brazilian masculinity. And it was not only Xavier’s own behavior that demonstrated this, but his presumptions about masculine behavior in general. He always attributed my need of protection to the “segundas intenções,” or ulterior motives, that other men would have in relation to a “beautiful, blonde American” who was so friendly with everyone.

These hypothesized intentions were simultaneously imputed to “natural” (i.e., uncontrollable, inevitable) male impulse, and contrasted with his “amizade pura” (pure friendship). In this vein, he questioned the safety of conducting interviews in the homes of couples I didn’t know well, and seemed anguished by my willingness to take the bus, alone, to neighborhoods entirely new to me. These were potentially valid concerns, but they were usually accompanied by an offer to help me get to know the city through a suggested outing with him, whether a tour that included a “romantic look-out point” or dinner at a club where he used to go during his drinking days. When I commented that this might be fun for the three of us (including his companheira) to do some time, he always had a reason for Juliana to stay home.

Such invitations, regular text and picture messages he sent me from his cell phone, and Juliana’s evident distrust of Xavier’s fidelity, coupled with the frequent hugs and kisses he tried
to give me led me to feel uncomfortable being alone with him.71 I tried various strategies to maintain rapport while re-framing our relationship, including ignoring what I felt was inappropriate, re-positioning him as a father-figure to whom I could safely turn for advice, responding to his insinuations with statements of *saudade* (homesickness/longing) for my significant other, and assuming a much more professional persona. None of this had any effect, and Juliana (in our private discussions) began to talk about how tenuous their relationship had become, largely because of Xavier’s inattentiveness and more frequent bouts of drinking. I mention this persistent dynamic here because it resulted in my decision to give up any attempt to conduct his formal (recorded), individual interview. Methodologically, this was less than ideal, but since Xavier normally dominated any interaction that included the three of us, it did not lead to an absolute lack of data.

Juliana was much more circumspect than Xavier; she readily acknowledged that she “can’t be bothered with most people.” Her face was heavily lined and voice roughened, whether primarily from years of smoking—the “vice” she couldn’t rid herself of—or from the cares of her 57 years, there was no way to distinguish. She was of slim build, with light brown hair and light skin. She smiled infrequently, but when she did, her blue eyes twinkled. I believed her when she told me that, at age 30, she couldn’t leave the house “*sem chamar atenção*” (without attracting attention) and making her then-husband jealous. Though my first impression of her was one of resigned pragmatism, she had a fun-loving streak and our one-on-one visits came to feel good-naturedly conspiratorial.

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71 As a matter of transparency, I note here that, during a previous fieldwork period in another Brazilian state, a similar, though less pronounced, dynamic turned unexpectedly and suddenly into a situation I felt was threatening. Because of this experience, I may have been a bit overly-cautious in my dealing with Xavier.
Juliana, like Xavier, was not in the best of health. She had chronic bronchitis which she attributed to smoking; despite seeking medical help, she hadn’t been able to break this habit. She’d suffered deterioration of her vision from cataracts and had surgery to correct them. It was also painful for her to walk. She said this was because her ankle had healed badly after a break; now doctors told her all the cartilage in her ankle was gone. She, like Xavier, was on a SUS waiting list for surgery. The operation would fuse the bones together, which was supposed to eliminate the pain, but would also mean the loss of functioning in the joint. She was ambivalent about the operation, despite reporting that the specialist who was treating her for this problem indicated that amputation of her foot would be the ultimate consequence of foregoing the procedure. She changed her mind about whether to go through with it several times during the period I had contact with her. Partially because of this issue, she didn’t leave home often, or roam very far when she did.

Although health concerns did impact her quality of life, she did not consider them serious in comparison to the heart attacks and “threats of stroke” she had suffered in the past. Attributing these to her tendency to keep all her frustration, stress, and sadness—especially in relation to Xavier and his behavior—to herself, she explained: “He’d yell at me and that stayed inside of me. From that, my cholesterol got bad because of my nerves, the stress. And from there I had a heart attack. In the next heart attack my heart stopped twice. So the doctor told me, ‘When you fight, don’t keep it in; if you have to break something, break it!’” Xavier acknowledged that, in the past, he’d had an “explosive” personality, but professed that when Juliana had the heart attacks he’d been scared to lose her. He insinuated that the couple had come to live a more peaceful life. For her part, in Xavier’s absence, Juliana told me this was
largely because she didn’t point out her partner’s failings or flaws; that would only lead to an argument.

Scarcely a month after we met, Juliana confided that she was reconsidering her relationship with Xavier. In fact, before I’d come to interview them the first time, she said she’d left for her sister’s house, in a suburb of Porto Alegre, and hadn’t planned on returning. Xavier had called her incessantly, asking her to come back. Then Juliana’s granddaughter, who lived nearby, had called, saying Xavier was in a terrible state and had gone to the health post. Worried, she had returned to find out that he was ill because he’d been drinking. “And he’s a terrible drunk, Shana,” she said, “He’s such a pain when he’s drinking, and for me…I’ve lived with a lot of alcoholics and now I have no more patience for that.”

In addition, both she and Xavier had previously noted his habit of going out and leaving her at home, watching TV or crocheting. In these behaviors, Xavier recalls McCallum’s (1999:284) summation of Brazilian masculinity: that the man “must be free to go out and battle in the world, earn money, spend it on drinking with his mates, or on sexual adventures.” Together, he and Juliana perfectly embodied the gendered dictates of rua/casa distinction (DaMatta 1984) discussed in Chapter 3.

Juliana said she missed going out, and having fun the way she had with past partners. I asked her to tell me about previous relationships she’d had, and to my surprise, she said, “For me, they were all great. I even miss some of them.” I attempted to clarify, feeling sure I hadn’t understood her:

Shana: Just now you said that you have no complaints about your past relationships, but didn’t you tell me once that one guy tried to kill you with a knife?
Juliana: My first husband, but that was because of alcohol...But he was a good husband. It’s the alcohol that made him act like that.
Shana: And did he drink a lot?
Juliana: He did, he lived his life drunk... Because city employees are like that, you know? They’re either drug addicts or drunks, or drug traffickers. So...

Shana: City workers?
Juliana: But he was a good husband...When he drank he was like that though. All drunks are like that, you know? They’re one thing [sober] and another thing drunk. Life is like that for us, with ups and downs and it just keeps going.

Shana: But how was he a good husband then?
Juliana: He didn’t let us want for anything: a good house with all nice things inside of it, my children were even a little too spoiled. So for me it was great.

The importance attributed to a man’s ability to fulfill the provider role (Ford et al. 2003; Knauth 1998) in this segment is unmistakable. In terms of material goods, however, she initially claimed she had no complaints about Xavier, either. Despite the fact that they lived on a fixed income—and that stretched thin—she said that she knew whatever she wanted he would try to obtain for her. By way of example, she said, “If I want to eat roast chicken, he’ll figure out a way to get it.” She also mentioned her desire for a refrigerator with a separate freezer compartment, called a duplex. Such an item would require more bargaining and more time to procure, but she was certain it was possible.

The house Xavier and Juliana lived in was made of cement and had two stories. The small, enclosed, ground-level porch outside the front door had the bars over the windows characteristic of houses that might contain anything worth stealing. This porch area was filled with a washing machine, and a collection of random objects piled haphazardly on top of each other. There were old electoral posters on the outside of the house. The front door opened onto a living room, with two, hard, upholstered couches, a TV, a stereo, and stairs, made of exposed, unfinished wood, leading up to a bedroom. Off the living room was a bathroom, and through the living room toward the back of the house, the kitchen.

Although the house was more spacious and seemed a sounder structure than many in the neighborhood, the newness of the electronics, and the quality of a couple of pieces of furniture
still presented a marked contrast to the condition of the living quarters. This was evidence not only of Xavier and Juliana’s preferred pastimes (listening to music and watching TV, respectively) but also suggested that their economic situation had been better in the past than it was when I regularly visited them. As Xavier said, “We’ve had good things, good houses…For one reason or another I had to keep moving/trading/downsizing until I got to this humble little house—that thank God we have, but we had better in the past.” To hear Xavier tell it, the couple had experienced a series of health and personal problems, which required liquidity to solve: “Sometimes, [money] gets tight; I have to sell something from here at home, out of necessity, right? Even if one buys it again [later]...Although no one wants to lose what they sacrificed a lot to gain. But that’s how we get by—the only way we can, you know?”

Negotiating this balance between resource inflows, unexpected expenses, and the desire for material goods was, predictably, a responsibility Xavier assumed. The particular way he discharged this duty was, I discovered, a sore point with Juliana, who wished for more dialog about household expenditures. The couple’s most basic needs did not seem to be in jeopardy, but money for discretionary spending was scarce and contested. For example, one day in the neighborhood supermarket, Xavier asked me to buy the tomatoes for lunch at his house. He explained that they couldn’t afford to eat meat or fruits and vegetables every day. On the other hand, his *companheira* frequently complained about how much money Xavier spent on his mobile phone; she noted that she’d had the same one for years while he had upgraded several times. It was also—according to her—not unheard of for him to spend R$40 in a day on pre-paid calling cards. “Who is he calling?” she vented to me, “I look at his phone and I don’t even know the people in his address book.”
The income upon which the couple depended for all these purchases was Xavier’s government pension. He was retired due to disability (aposentadora por invalidez), and earned two minimum salaries (about R$800) a month. Juliana had no pension and was unemployed, leaving her with no steady income. Importantly, those conditions had not changed in the recent past. Therefore, in order to make sense of Juliana and Xavier’s claim of a decline in their living standards, one must understand the common and important practice of generating alternative revenue in the informal economy, including amongst those who receive government benefits. In the past, Juliana had made and sold handicrafts, and Xavier had been an ambulatory umbrella vendor. The couple had also worked together for a while, selling snacks and sundries out of a stall they improvised on the side of the street. But these days, according to Xavier, no one had money to buy the kinds of quality, handmade goods Juliana sewed. Everyone was in the same economic straits, in part, he said, due to the financial crisis that had begun in 2008 in the U.S.

In addition, the couple’s physical condition had changed: “She isn’t healthy enough to work outside the home, and me, after I had my accident, I’m not either. I have to use this cane and everything.” In other words, their health had deteriorated to such an extent that it was no longer possible for them to work to supplement Xavier’s pension. By law, of course, it is illegal for Brazilians receiving disability benefits (whether retirement, aposentadora por invalidez, or temporary assistance, auxílio doença) to work, given that, if they’re healthy enough to work, they shouldn’t be receiving such assistance at all. And yet their previous ability to supplement this income was what had made their economic situation, in their eyes, tenable. Now more constrained in the types of strategies they could employ to earn money on the side because of their physical condition, they were also more hesitant to attempt to do so because getting caught
would mean the loss of the only dependable income source they had. Emphasizing how terrible this would be, Xavier said in an interview, “That would be it—we’d really be underwater.”

In the next breath he admitted that there are cases of people receiving disability benefits and still subsequently being discovered doing very physical labor. He says that is a polemic, but he only works because he really needs the money. And to prove his point he explained that he had taken out six loans over the last couple of years. I asked him what had caused him to accumulate these debts. He said, “to move, to fix the house, then to buy the motorcycle, and because of other problems we had. And then it becomes this thing that we get and later we’ll pay for the rest of our lives, and it eats away at our salary, you know?” After paying what he owes every month on these loans, he says the couple is left with between R$200-250. This is enough to keep them fed, partially, he explains, because at the corner convenience market they can “buy things in the notebook” (this was the storekeeper’s version of buying on credit), and because banks were required to extend a minimal amount of credit to the poor (“o limitizinho do banco”). While some of these loans were necessary, he admits that he didn’t know how to put others to the most advantageous use. Now they take portions of his pension that he says could be used to “give better things” to Juliana, things that he said she sometimes reminds him she’d like, which hurts. He claimed that, were it not for these loans he now had to repay, he “could live like a king with those 800 reais.”

Thus, most of the couple’s attention and energy was directed toward making ends meet and gaining a bit of security, attempting to get along amicably with one another, and dealing with their most pressing health issues. Significantly, the latter did not seem to include Xavier’s HIV. Neither the infection itself nor the experience of treatment for it ever spontaneously came up in our conversations, although he had discussed this with me the first time we met, at the clinic.
During the couple’s formal, joint interview, I was the one to inquire about the subject—after an hour of talking.

Xavier had been diagnosed about 14 years before I met him. He had not sought out testing because he had fallen ill, but because, as he’d begun to hear about AIDS, he suspected he could be infected, given his injection drug practice and the death of an ex-girlfriend of his from AIDS:

So I was going to go [get tested] back then when I suspected it; I had a girlfriend at that time that died from the illness and I was in the same stuff, right? So, I went, did the tests, and the psychologist said, ‘Look, sir, on such and such a day it will be ready, you can come here and find out the results.’ Well, what happened? The day to go there and find out arrived and I was just in agony: ‘Gosh, how’s it going to come out?’ So I was in line, that line of people they have there, right? After a bit I saw one come out crying and I thought, ‘Eeeeee!! That one there, from the looks of it, got the result.’ And then one would come out with a smile stamped on the face and I said, ‘Hmm, it went well for that one.’ And we were watching these details, only, when it got to be my turn, I started letting people go in front of me. I had a stomach ache, there was this situation: ‘Now it’s your turn, ma’am.’ ‘No, you go ahead, sir.’ ‘No, you can go since I’m going out to get a drink of water.’ So I went out and got some water and was going to go back to pick up the results and I said to myself, ‘I’m not going to pick up anything!’

He left. He said he returned four or five times before he forced himself to go through with receiving the results, even though he was “90% certain [he] was already infected.”

Awareness of how some of his actions had put him at risk did not make it easier to hear the diagnosis: “When I found out, there, I got so down…I was on the floor, right? … I got out of there and drank and drank and we didn’t have anyone to open up to, you didn’t go out on the street, ‘I just went and found out that I have—,’ No!”

This leads the couple to talk about the existence of HIV-related stigma, and the persistence of misconceptions about transmissibility. Juliana insists that there are still people who believe you can get HIV “from a cup of water, from chimarrão.” She says she protests these ideas when they come up in conversation, but subtly, by making a remark along the lines

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of, “I never heard you can get HIV like that.” She clarifies, for my benefit, that she knows one can only get HIV from sex, or from open, bleeding wounds. She says this information is available to people, for example, on television, but they don’t always pay attention. Xavier agrees, adding, “Discrimination, because of color [that is, race] and HIV alike, is very present still.”

Although he was open with me from the start about his HIV status and how he had acquired the infection, fear of stigma seemed to lead Xavier to be somewhat guarded about his seropositivity more generally. He never mentioned HIV outside of the clinic or his home; unexpected visitors to the house always prompted a suspension of our conversations. On one occasion, we were in the midst of discussing how Juliana’s children came to find out about Xavier’s serostatus when a group of family members arrived, including some of the very people we’d just mentioned. However, the group included more distant kin and children, and it was clear, as I was introduced to various individuals, that the reason for my presence that afternoon was to be elided. HIV was not acceptable small-talk.

This was not surprising, since the couple had initially chosen not to reveal Xavier’s HIV to Juliana’s children at all—not, as she explained, because they anticipated a negative reaction from her sons and daughter, but because maintaining secrecy minimized the chances of inadvertent, extra-familial disclosure. They were prompted to break their silence by situations in which this knowledge might provide comfort. The first was a dramatic turn of events in the life of Juliana’s daughter. After years of marriage, the daughter’s husband had suddenly lost a significant amount of weight, and confided to his wife that he feared being HIV-positive. She encouraged him to get tested. According to Juliana, what her daughter hadn’t known at the time was that the husband had been diagnosed with HIV several years previously, subsequent to an
affair he’d had, but never told her. After learning of his serostatus, the daughter, desperate, sought out her mother for support, convinced she must be infected as well. In order to ease her daughter’s anguish while she waited for her own results, Juliana and Xavier decided to “abrir o jogo” (lit., “open the game,” or come clean with all the details). They told her not only that Xavier was HIV-positive, but that Juliana was not, despite years of an active sex life that had never included condom use. Juliana’s daughter’s test result was negative. As Xavier concluded the story: “She’s got blood just like her mom—she doesn’t get [HIV].”

In response, Juliana noted that she goes to the nearby municipal testing center every year for an HIV test. She says that after seven years the personnel there have dispensed with the pre- and post-test HIV counseling required by law in Brazil: “They’re tired—I don’t even do the interview part anymore, you know. I just come in and say, ‘I want to be tested…They say, ‘Bah! You’re crazy; you don’t use condoms.’ And I say, ‘I just can’t do it, I can’t.’” When I press her as to why she “can’t” use condoms, she says matter-of-factly that the doctor who performed her episiotomy when her daughter was born told her she couldn’t. Subsequent attempts to use condoms (both male and female) produced inflammation and pain that required medication and took days to subside; the lubricating gel she obtained at the testing center did not minimize these effects.

She shrugged and continued, “So I told [the testing center personnel], ‘You just have to ask God [to prevent infection]…If I have the bad luck to get it, what is it that I’m going to do? Start the treatment. It’s the only way, because what can I do? Leave the relationship? ‘I’m not going to abandon you,’ I said to him [Xavier]. After seven years? I can’t jump ship…No, I got married, got together with him knowing.’” When I ask her if she’s afraid of getting the virus, she says, “I’m not afraid of anything. I already died three times, and here I am. The doctors say I
have the lives of a cat, the soul of a cat.” She laughs and adds, “Death comes when it will; there isn’t a specific day or hour or illness that kills.”

Nothing Juliana ever said indicated that Xavier’s HIV status had been problematic for her, although he had been very apprehensive about the way she might react to the initial revelation. The couple met because Xavier was friends with the man who eventually married Juliana’s daughter (and later had the affair), and frequently visited this friend’s house, which was just a few doors down from where Juliana was living. Despite the fact that both of them were in relationships with other people at the time, several weeks of flirtation ensured. Though the details about who-pursued-whom differed according to which member of the couple told the story, they both shortly became single. Xavier felt he had to tell Juliana of his serostatus before beginning a physical relationship with her, but this prospect was daunting:

I said to myself, ‘Dang, and now she’s taken a liking to me and I’m in this situation. I like her too, but when I tell her [about being HIV-positive], how is she going to react?...I just said, ‘Never mind, this is how it is, so let’s just leave it, we’ll just be friends.’ Because there are people who turn their backs and slowly become more and more distant from the person [who disclosed]… and they tell other people and act strange on top of everything, which just makes us feel more uncomfortable, you know?

Despite these fears, he persisted, mulling over how to tell her for four days. He finally arranged to talk with her, but as the moment drew near, he wavered, in fear of her reaction. Even almost eight years later, as he told the story of disclosing his HIV status to the woman who had become—for practical intents and purposes—his wife, the tension and anxiety was apparent:

I took a couple of gulps of a drink we were having and I said, ‘Look, I’m going to tell you something. I know that you like me and you’re ready for something to happen between us, you know, something more than just friendship, so...but I hope that... that, I don’t know what attitude you might take—the feeling in my heart is going to count more for me than hearing a ‘No.’ I’m prepared to hear a ‘No’ from you rather than do something that might end up hurting you and tomorrow have that heavy conscience and experience other reactions a person can have afterwards, you know. Or even attacking the person, right? Look, I’m not going to
sleep with you and then after the fact I say, “Look, I’m…” From that someone can pick up a knife and kill you right then [saying], ‘But why didn’t you say this before?!’ [laughter from Juliana and Shana] Right? So I say, ‘No, it’s like this…Look, unfortunately I, because of a slip-up that I had and so on and so forth, I…am…I’m HIV-positive, you know? If you like me, if you’re there and want to continue to like me and want to have something with me, we’ll use a condom, we have them right here…If you don’t want to, I hope that you won’t discriminate against me, that you’ll at least be my friend, because I’m seropositive and no one is immune [“free from that”]. I hope that we can have a good friendship. Because I’m being honest with you I think I deserve at least your friendship, you know? Because I don’t think you would like it if I used you and after that told you. …And she said, ‘No, that’s fine, since you’re being honest with me and telling me, I will…We will…you know?’”

Juliana later said she imagined it must be difficult to disclose one’s serostatus under such circumstances. She told me in private that Xavier had “cried right in front of [her]” because he anticipated being rejected. This seemed to make sense to her, prompting her to mention again the misconceptions about transmissibility of the virus. She, however, said she’d known HIV-serodiscordant couples who lived in her neighborhood from the time her children were young, and she saw them share drinking glasses and cigarettes and the women remained seronegative. She didn’t discuss those women’s sexual practice, but instead simply restated the primary means of transmission. Her implicit message seemed to be that HIV is not that easy to contract. This was accentuated as she continued:

Juliana: I have to take care of myself. Place myself in the hands of—the one up above, right? God knows what He’s doing. Just to show you, I’ve been with [Xavier] for eight years and, thanks be to God, nothing. His [virus] is paralyzed, you know.
Shana: Yeah, his viral load is really low.
Juliana: So there’s no way [for transmission to occur], the doctor says. But I could get Hepatitis. But I don’t get that either.

Despite years of exposure, Juliana remained seronegative; indeed, she constructs transmission from Xavier as impossible, and invokes biomedical authority to sanction this interpretation (although I never heard any practitioner at the clinic even hint at such an
interpretation). However, on other occasions, her portrayal of the likelihood of seroconversion was different. She noted that many people contract the virus and pass it without knowing they’re infected; the diagnosis is not, she noted, “written on anyone’s forehead” after all. In this rendering, anyone can have the virus and she said, “It’s easy to get.” In addition, when she told the story of her ex-son-in-law’s affair, she indicated he had brought the infection on himself by sleeping with someone he knew to be HIV-positive—as though transmission were the foregone consequence of this action (in juxtaposition to her own experience).

Juliana never directly addresses these divergent assessments of transmissibility, so we don’t know whether she sees her case (and her daughter’s?) as exceptional, or what relative weight she would accord—in reference to her own situation or more generally—particular behaviors, viral suppression, (bad) luck or God’s will, or some sort of immunity on the part of seronegative individuals. She denies being concerned about seroconversion, including it in the “nothing” that she fears more generally. This professed lack of apprehension might also stem, at least partially, from the fact that Juliana believes “there’s no way” for Xavier to infect her. Nonetheless, if this were to come to pass, “the only way” to deal with it would be to “start the treatment.” Juliana’s conception of HIV, particularly regarding transmission (and, hence, risk), is clearly informed by biomedical understandings, but not limited to them. In a sense, her knowledge about the virus and available treatment, rather than influencing her to minimize her exposure, serves as a justification or an insurance policy for what biomedical practitioners label as “crazy” (read: exposure-inducing) behavior.

Juliana’s apparent acceptance of the possibility of seroconversion was, however, not due to any belief on her part that her relationship with Xavier was necessarily permanent. In fact, over the course of her formal individual interview she returned multiple times to the phrase, “I
don’t know for how much longer this is going to be my life.” She spoke at length of various ways living with Xavier could be corrosive—his demands in terms of housework, their lack of shared interests, the cessation of the attention he used to pay her, her growing suspicions of his infidelity. In these stories there was usually a “character,” so to speak, that took Juliana’s side, or at least expressed concern for her. In one example, she recounts an incident that took place when Xavier was hospitalized (less than a month prior to this conversation). The couple had needed cash; given Xavier’s confinement, Juliana was uncharacteristically responsible for getting it. She explained, “Since I had never made a withdrawal, and I hadn’t—I’d never even dealt with an ATM, so I did something [accidentally] that he didn’t like.” A serious fight ensued when she returned to her husband’s hospital room, which came to the attention of the nurses on the floor. “They thought I was going to have an attack. I left and I was white as a sheet. I left and all [the nurses] were calling me, to give me some support. I went to the visitors’ restroom to cry.”

This seemed to push Juliana to the edge, and she threatened Xavier: “The day that I walk out that front gate, my cell phone will be off. It will be turned off. Because that will be it.” Hearing these stories prompted me to ask why she stayed. She gave several answers. Referring to the specific episode above, she said, “But I like him; if I didn’t like him I wouldn’t be with him anymore. As they say—What happened in the hospital? If it had been someone else, I would have left him.” Later she added, “I haven’t left him because I feel sorry for him. He doesn’t have anyone....I’m certain that when I walk out, he’ll get right back into drugs. You see? I don’t want to have that on my conscience, you know? That’s why.” On the other hand, she ruminated, “There are times I think that I’m with him also because I have a right, you know? The money is half his and half mine. I contributed too—what [capital] I had I put [into this
house]…I wasn’t living on the street before this.” Thus, it seemed that emotional bonds, the feminine duty of caretaking, and economic (inter)dependency all contributed to Juliana’s decision to remain in the relationship. In the context of what I knew about their relationship, I wondered if, in addition to the physical discomfort she reported (which I believe was genuine), the same factors didn’t also have a role in the couple’s dispensation with condoms. I would have no further opportunities to attempt to unravel this etiological knot.

After a series of missed phone calls, I finally was able to speak to Xavier prior to leaving the field for a month at the end of 2009. He was adamant that I should not leave Brazil for good without coming to say goodbye to him and Juliana in person. I assured him I was only leaving for a short while. Nonetheless, I took to stopping by their house whenever I visited the adjacent clinic. After a few attempted visits during which I found no one home, I left a letter for the couple, promising to visit as soon as I returned. Similar difficulties plagued my first attempts at communication after my return in Porto Alegre in January of 2010. When I was able to connect with Xavier, I learned he had been interned at a local hospital for problems with his liver—a product, I assumed, of a drinking binge. Such circumstances, if true, did not, I thought, bode well for the health of his relationship with Juliana.

When I was able to visit, I was ushered into the familiar living room and asked to sit down before they told me they had big news: they were no longer a couple. They still lived together, but slept in different rooms; in essence they had divided the house in half. Both asserted that they were getting along better now than ever, although Juliana looked happier throughout this discussion than Xavier did. If their past history served as any guide, it seemed likely that both were on their way into new relationships.
Renato & Milene

Renato’s smile was the warmest in the waiting room, despite his slightly bashful demeanor. His appearance suggested he had taken care, within limited means, with his visual presentation. The day I met him, he was dressed casually, in jeans and a sweater. He was clean-shaven and the pink undertones of his skin made him look almost cherubic, even though his hair—curly and cut fairly short—was dark brown, if not black, and matched his eyes. Although I later discovered he worked at a paint factory, I never saw paint on his hands or fingernails. He was 35 years old.

He told me almost immediately that he’d been diagnosed with HIV 13 years previously. He’d gone to the doctor about a skin lesion that wouldn’t heal. When an HIV test was suggested, Renato agreed with “the greatest sense of calm, a clean conscience.” At 22 and quite shy, he said he had been a virgin. Therefore, the positive result he received was “a horrible shock.” He said he could only have contracted the virus a few years prior to the appearance of the lesion, when he had been hospitalized in a rural area with a gastrointestinal infection. According to Renato, both he and his mother had seen a glass syringe used for one of the injections he’d received. This he called his “deepest sorrow.” Because he had not been “doing things to expose himself to risk,” he could not accept the diagnosis and sought psychological help. He was not physically ill, however, and said that although the diagnosis made him very sad, it didn’t affect his daily routine. At the time he was pursuing the Brazilian equivalent of a GED, which he completed. After that, for two years, everything was “normal.”

When he was 24 or 25, however, Renato’s doctors began prescribing ARVs and he noted, “that’s when there was another collapse—but not in my health; in my head. [I thought] Oh, I have to take the medicine, because I’m dying!” During our first conversation, he emphasized
how much his thinking had changed on this issue by foregrounding his current habit of helping
others adjust to the reality of living with HIV. He said he sees people struggling, crying over
their diagnosis and he asks them how long they’ve known. “They say a year, two years. I say,
‘Look at me; I’ve had it for ten years—more! And they say, ‘What? But you’re chubby!’” He
says newly diagnosed patients still suffer under the assumption that they’ll soon look skeletal,
like Cazuza, a Brazilian rock star who died of AIDS in 1990, “but that was at the beginning [of
the epidemic].”

Renato also tries to be a positive role model for his ten-year-old, seropositive neighbor.
He shows the child his own pills, then explains the regimen the boy has been prescribed: which
pills to take when, and why it’s so important not to skip doses. “He’s a kid, though, and his
[grandmother] doesn’t make him [take the medicine].” Renato may feel particularly keen on
providing such support because, as he later revealed, he had previously stopped taking his own
medication twice. Never having fallen demonstrably ill, he simply could not accept his need for
ARVs. At one point, he was frequenting a church that claimed to have cured him (several
patients told me the Universal Church of the Kingdom of God, or Igreja Universal do Reino de
Deus, often made such claims, although Renato avoided specifying in his own case), and he
abandoned his treatment. Although his health did not seem to deteriorate, he finally convinced
himself that taking the medication was necessary.

Due to these periods of non-adherence, in order to prevent potential viral resistance
Renato had gone through two previous trocas, or changes in the particular combination of drugs
being used to treat his HIV. At the time I met him, the regimen he was taking included a drug
called Norvir, which required refrigeration. In other neighborhoods, Norvir would not have been
problematic; in Renato’s, I knew the electric current was prone to surges and blackouts. Indeed,
during the period of my fieldwork, Renato’s household had to purchase a new range after a fire caused by a power surge melted the burners on the one they’d had. It remained to be seen, however, whether Renato’s regimen would remain dependent on refrigeration; several months after I met him, he faced another troca. The arrival of summer had revealed his slender legs and protruding belly, a textbook case of lipodystrophy, according to his doctor. Despite an undetectable viral load and high CD4 count, serological markers of treatment success, Renato’s physician wanted to substitute at least one of the drugs in the cocktail.

Whether due to this alteration in his medication or a different perspective on his health in general, Renato talked much more, and more spontaneously, about HIV and ARVs in our interviews than other seropositive participants did. He said he rarely forgot about taking his medication, but highlighted the emotional stress of adherence: “I’m used to it, but sometimes I feel depressed…it hits you that this is a prison!…Because you’re dependent on [the medicine]…You’re on a schedule for everything…always, always, always.”

This statement contradicted the predominant and recurring theme of my conversations with Renato, however, which was normalcy, and more specifically, “a normal life.” He contrasted the rough period he’d gone through while adjusting to the idea of taking medication to the present, saying, “So today I live normally!...As you can see. I mean, I—People who see me, they see how healthy I look and say, ‘No, that’s a lie. You’re lying [that you have HIV].’” After sharing the story of another seropositive acquaintance who had been hospitalized, Renato returned to his claims of “living a normal life,” which he juxtaposed to his friend’s experience. I asked him to explain to me what “a normal life” meant. He replied, “Normal life. How can I say it? A life as though I didn’t have [HIV]. As though I weren’t seropositive. And it [meaning, HIV] doesn’t really come up. Here at home, I mean.”

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72 The maldistribution of body fat, a side effect which can be caused by ARVs.
Toward the end of his individual interview, he elaborated a bit more on this idea when I asked if he had any advice for couples who had just discovered their serodiscordance. In addition to foregrounding the necessity of initiating treatment for the seropositive partner, he counseled: “And try to live as normal a life as possible. “Normal” is a relative thing, but try to live without—without the trauma of the disease. That’s what I think. I tried to live without the trauma of the disease. And always going to the doctor, to keep up with things. That’s my case; I’m on top of things. That’s all, at least for me.”

Despite his portrayals of this normal life, however, later in the interview he picked up on the prison theme again: “It’s just that sometimes, dang! I would get depressed, you know. That’s a prison, a prison without bars...and you’re stuck there. Thank God I have Milene and Ivar...they pick me up when I’m down.”

Mileen is Renato’s common-law wife of three years and Ivar is her four-year-old son from a previous relationship. The three of them live together in Renato’s two-bedroom house, in the neighborhood adjacent to the clinic, and several blocks down the street from another couple in the sample, although to my knowledge they did not know each other. The exterior walls of the one story house were of cinder blocks, covered with concrete. The front door did not face the street, but opened to a small side area where Milene had a clothesline. The tiny lot was enclosed by a waist-high fence with a gate: no obstacle for adults wishing to gain access, but enough of a barrier to keep small children and the family’s puppy from entering or leaving undetected.

Inside, one passed through the living room to get to the kitchen; the bedrooms were off to the right and the bathroom at the back of the house. The concrete floors were uneven and, in some places, covered with overlapping pieces of what looked like plywood. The walls subdividing the rooms often did not extend all the way to the ceiling, perhaps because there was
no ceiling to speak of, only the roof. The little house was stuffy in the summer, drafty in the winter, and the roof leaked whenever it rained. The home had running water and electricity, although, as noted above, the electric current was not entirely dependable.

Milené and Renato had met when they were employed with the janitorial service at the Postão. They saw each other occasionally, in staff meetings and sometimes in passing, but Renato worked in a secured area of the post, while Milene worked in various other sectors, including the HIV counseling and testing center (COAS). Their accounts of the beginning of the relationship coincide: it was Milene who pursued an initially-oblivious Renato. As Milene tells it, she was interested in him, and dropped hints to that effect, at one point even maneuvering him into a corner to talk, but he hadn’t picked up on her signals. He agreed, saying “I am really spacey like that.” Milene noted that he was seeing another female co-worker at the time. Renato later clarified that this “relationship” was his first since being diagnosed, ten years previously, and lasted only three days.

Monday after the breakup, Milene could see that Renato was sad. She says she commented to him, “Maybe you should look around. There could be someone right next to you…,” she trailed off. He remembers her saying, “To get over a love affair, you need a new love.” They agree that’s when he finally realized what was going on. Her usual route home from work took her close to his house; that day he waited for her and they walked together. Along the way they held hands and Milene was the one who pulled him close for their first kiss. She jokes with him now: “I practically had to rape you [to make my feelings clear]!…(to Shana:)

All our co-workers knew I liked him, but he didn’t!”

During the very first conversation I had with him, Renato had spoken of nearly despairing of ever finding anyone who would “understand him” before he and Milene got
together. But just a month after their first kiss he had invited her and Ivar, her son, to move in with him. They had been together ever since. When I asked what he had liked so much about her, he said it would be disingenuous to deny that he’d initially been attracted to her physically. But he quickly saw what he called her “internal virtues” and said: “Today, she lifts me up. She brings me back to reality because—especially because I’m a Pisces; I’m spacey, I live ‘on the world of the moon’…and she brings me back to reality…she’s a great companion. Yeah. She’s everything to me…she completes me.” His voice drops as he utters these last two phrases; he says them simply, quietly, wholly.

Milené had a list of qualities she liked about Renato when I asked her the same question. He was sweet, calm, not violent, treated Ivar like his own son, understanding (“maybe even a bit too much”) and a good friend with whom she could talk about things. “We get along super-well day to day…I’m the one that fights with him, not him with me,” Milene explains. It was evident from interacting with them that she had the more tempestuous personality of the two. She loved a good story, and often regaled me with the dramatic goings-on in her neighborhood, despite my having met only a few of the protagonists. She could be light-hearted and impish, yet she had lived through the early death of her parents, a period of near-indentured servitude with her guardian’s family, and a series of relationships with violent men, one of which caused her to flee her hometown in fear of her life.

Her shoulder-length, light brown hair fell into soft curls, and her big brown eyes and button nose made her look younger than her 30 years. She could not have been taller than 5’2”, but there was an unmistakable air of determination about her. One felt Milene could handle whatever life might throw at her. One also felt (and she acknowledged) it was best not to cross her. She had, for example, fought with the family of their 10-year-old, seropositive neighbor
over what she saw as their failure to take responsibility for his proper care. Avoiding a physical confrontation (barely), she nonetheless reported them to the government agency charged with the protection of minors.

Her own son occupied much of Milene’s attention. Ivar, at four years old, looked more like a six-year-old to me. He was very physical but was almost always playing a video game or watching a movie when I arrived at the house. This may have been Milene’s way of keeping him occupied while we were chatting. I never saw him outside with the group of kids whose shouts and laughter often filled the air, a raucous human tumbleweed blowing through the neighborhood in search of diversion. Other than the streets, there didn’t seem to be much of a place for children to play, and the stories Milene and Renato occasionally told about stray bullets, police chases, and drug dealers made me think they did not consider it safe for Ivar to go out without their supervision.

Money was tight enough that taking the bus to another location where Ivar could play (the bus that I took to and from their house, for example, passed by one of the best-known parks in the city) was not often an option. Even if money had been no object, however, Milene frequently was not physically capable of taking Ivar anywhere. As mentioned previously, Milene and Renato had met as co-workers in the janitorial service at the nearby health post. At that time, Ivar was in daycare. After they moved in together, however, Milene began experiencing pain in her back, hands and feet. She said she had tendonitis, and was diagnosed with a synovial cyst in one of her hands, for which she was awaiting surgery through SUS. As she is ambidextrous, she resorted to using the other hand, but began having the same problem. More recently she developed what she called an “infection” in her spinal column and pain in her feet; doctors were trying to discover the cause, but X-rays showed nothing. Physical exertion
was painful and sometimes precipitated the loss of strength in her limbs. She noted during one interview that, just days prior, she had carried a very sleepy Ivar to the bathroom, and was holding him over the toilet (allowing him to urinate without totally waking up) when she suddenly could not sustain his weight. If Renato hadn’t secured the child, Ivar would have fallen. In the months that I visited her at home, increasing pain in her joints was an overriding concern for her.

It had been a year since she’d had to leave the janitorial service. She said she was able to take care of housework by taking advantage of her “good days” to do things like wash clothes and clean floors, and relying on neighbors for help. This level of disability was problematic not only in domestic terms (housework and childcare), but economically as well. Milene told me she had applied for temporary disability (auxílio doença) six times. Each time her petition had been denied. More physicians had been consulted and tests had been ordered in order to substantiate her claims, but in the meantime she was receiving no financial assistance.

This situation would have caused incredible hardship for the family had their income not increased since the beginning of the relationship. In 2007, Renato, at Milene’s urging, had applied and been classified as “partially disabled”—not due to his HIV serostatus, but as a result of the use of forceps at his birth. Renato had undergone years of physical therapy in order to walk normally, but, as Milene told me, “one side is still longer than the other.” Having been so-classified by a physician, he was able to obtain the job he held when I met him, at the paint shop. There, what he earned by himself, take-home pay of around R$600 per month, nearly equaled the couple’s joint income when both had been employed in the janitorial service.73 In addition,

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Milene explained, because he was employed as a disabled person, it was much more difficult to terminate his position, affording the family a measure of security.

Nevertheless, Milene says that money is tighter now than before, because “when I was working, I kept track of my earnings, and once a month we could go out to a pizza place or a grill to eat. Now we don’t go anywhere because of his craziness.” The “craziness” Milene refers to is Renato’s tendency to spend money on things she sees as unnecessary: two sets of summer clothes instead of just one for Ivar, a more expensive type of cracker or cookie than she would buy, etc. She insists that every time Renato goes to pay the bill for their department store credit card, he comes home having purchased something as well. These less thrifty choices mean that, whereas she would save a bit here and there that would add up to enough to take the family out to eat at the end of the month, there isn’t anything left over when Renato administers the family’s money.

Thus, financial concerns and Milene’s health were the main obstacles the couple was dealing with during the months I visited them. Although HIV was not a taboo topic in their home, neither did special importance seem to attach to it. Renato had told me the first day I met him that he and Milene did not regularly use condoms to prevent HIV transmission. The exchange was memorable due to a linguistic mistake I made during the course of our conversation. My fieldnotes from 27 August 2009 record the episode this way:

> He and his wife don’t use condoms and she’s [seronegative]...He thinks the fact that she hasn’t been infected [despite lack of prevention] is because he has an undetectable viral load. His CD4 is high. He says he’s more worried than she is about transmission. I said, “Tu acha?” He said, “Não, de fato.” When she went to do her test and it didn’t come back on time he was crying. She said, Don’t worry. And it came back and she was fine.

When I said, “Tu acha?” (literally: “You think so?”) I had meant merely an encouraging, “Oh, really?” but the connotation of those words in Portuguese is something more along the lines of,
“Is that your opinion?” That is what Renato responded to when he answered me, “Não, de fato” (literally: “No. In fact.”). His response should be understood as “No, I don’t ‘think’ so, I know so!” As such, he was taking his assertion out of the realm of belief and placing into the realm of fact: he worried about his wife’s potential seroconversion more than she did (as do many positive partners in serodiscordant partnerships, e.g., Beckerman 2002; Amorim and Szapiro 2008).

The stories the couple told seemed to support his assertion. Milene and I talked about it the first day I visited her at home. Later, during a recorded interview, she re-told the story of the first time she and Renato had been physically intimate:

So we went to the bedroom but it just wasn’t happening. And I told him, If you don’t want to do this, all you have to do is say. And he said, No, that’s not it. It’s that… I have HIV. So I said, Well, that’s fine, we just have to be careful. So he put a condom on and –pffft (makes a falling motion with her hand). No way. But since I really liked him we started anyway, and to this day we do it without a condom.

On another occasion, I asked what her first reaction had been when Renato told her he was HIV-positive. She was characteristically direct: “I said to him, Ok! And he said, ‘Are you joking?’ No, I’m not joking. I could have gotten some other sneaky bastard, and instead of, for example, having Ivar, I could have HIV right now! And he [said]: That’s true; it’s good you see it that way. [I said:] At least you’re telling me the first time. Then…I can decide if I want to or not.”

The fact that she could easily have contracted the virus before even meeting Renato is an idea that recurs in Milene’s talk. Frequently, as in the above example, this is accompanied by a statement rendering an implicit judgment: that choosing exposure and potentially becoming infected through sexual contact with Renato is “better” than becoming infected through unwitting exposure with her previous sexual partners. I knew that COAS had been one of the areas Milene was responsible for when she worked at the Postão, and that HIV was not,
therefore, a novelty to her when she heard Renato’s disclosure. Nonetheless, the story struck me as almost too seamless. I asked her about dispensing with condom use: was this a decision they made together? Her response was immediate:

Milene: No! It was automatic!
Shana: Really?
Milene: Yeah! I was already on fire then. I was in the [moment], you know? And it went.

Thus, in her telling, the possibility of contracting HIV, the mechanics of which Milene knew well, was no match for her sexual arousal.

Acting on such desires, despite what others might understand as potentially negative consequences, was not new for her, however. After losing her parents early in her life and becoming estranged from her guardians, at 17 Milene was essentially independent. She initially lived with a roommate, another young woman, but the neighbors began saying that the girls were vagabundas, which can translate as “slut” or “prostitute.” She continued, “I had a lot of men in my life. Being a vagabunda isn’t derogatory to me, or for anybody else, you know? It’s just a woman that’s had several men.” Hers, it bears noting, is not a typical interpretation of this word for speakers of Brazilian Portuguese; in my estimation, calling a woman by this term would usually be sufficient to start a fight. Milene emphasized to me that, contrary to what I might have assumed, she did not move out over such disrespect. The conflict that prompted her departure, Milene explained, was that her roommate brought home lots of men, some married, with wives who then came around and made problems, but forbid Milene from having her one boyfriend over to the house. She left, then, to secure a greater measure of sexual-affective freedom.

She appealed to an aunt for assistance, and the ensuing living arrangements led to Milene beginning an intimate relationship with one of her aunt’s sons. She described this partner as one
of the two “husbands” she had prior to Renato, although she’d never been formally married. The relationship soured quickly, amidst alcohol and physical abuse, and Milene left him. Her next “husband” also had a history of violent behavior toward his partners, but had never beaten her before they moved in together. Although she was working outside the home at a video rental shop, he was very controlling. Then the abuse started. Her first, unsuccessful, attempt to run away from this man led to him habitually hiding the keys to the house when he was not out (it is common, as a safety measure in Brazilian homes, for the door to be locked from the inside; without the key one is basically trapped). Nevertheless, she’d discovered his hiding place. She recalled how he had kept her locked in the house at the end of the relationship: “That day he woke up, it was a Monday. He woke up at 7am. And I told him he wasn’t my friend. And that was the last time he beat me. Then he just...stayed awake. From Tuesday to Wednesday, from Wednesday to Thursday…When he fell asleep at 4am [on Thursday morning], I said: It’s today. It’s now or never.”

After he fell asleep, she grabbed a small bag she’d previously packed and the house keys. Letting herself out quietly, she locked the door from the outside and took off for the bus station. She hid in the women’s restroom, only coming out to check the time so she wouldn’t miss the 8am bus to Porto Alegre. This had taken place six years before I met her; she had never gone back.

Her brother was living in Porto Alegre then, and she stayed with him for a time. She continued to have relationships with various men, but the only one she deemed noteworthy enough to talk about at length was with Ivar’s father. This relationship was a frequent, if implicit, reference point for her, not for its emotional quality, or even solely for the birth of her son, but also for what it had led her to reject, and the consequences of those choices.
The story of Ivar’s conception was told in response to a question I asked about Renato—even though Renato is not Ivar’s biological father. I asked Milene how many people she thought also possess the qualities she’d listed as Renato’s admirable attributes. She’d said he was the only one she’d ever met. Then she elaborated:

Sometimes I tell [Renato]: ‘If you weren’t the way you are, I wouldn’t be with you.’ Especially because I have to think about my little boy before [anything else], you know? Ivar’s father is in jail. I got together with him a few times but when I found out who he was [i.e., that he was a drug dealer] I ended it. He kept threatening though. I lived with my brother and [Ivar’s father] kept threatening my brother and my niece. I was forced by him. The day I got pregnant with Ivar…it was with a revolver at the side of my head…And I grabbed the gun—he had taught me how to shoot. I grabbed the gun…to shoot him. I didn’t have the courage, but that was my idea! The last fight we had, I told him…that I would rather have a child with my dog than have his baby.

Clearly, this relationship was not meaningful in an emotional sense to Milene. Although she noted the physical attractiveness of Ivar’s father, she spoke of him with disgust. This was not merely due to his conduct toward her, or the physical abuse she knew his other sexual partners suffered. It was also not strictly a result of his profession. What came in for special condemnation was his willingness to use his children in the drug trade, something Milene claims she personally witnessed, and could not accept for her own son. Rejecting her erstwhile partner’s offer to provide housing and money for living expenses for her and the baby (which, as a dealer, he was in a position to make good on—at least as long as he remained alive), Milene dictated strict terms under which the father might have bi-weekly visits with their son. The last time Ivar’s father saw him, the little boy was seven months old.

Once Milene was pregnant with Ivar, she seems to have decided to break with many aspects of her past. She stopped drinking and applied for government assistance, which enabled her to move into a shelter. She used different criteria to select potential long-term partners. Instead of a decisive priority accorded physical attractiveness, acceptance of her child and a less
violent disposition had risen in her esteem. To emphasize how important this was, she told anecdotes of women she knew whose children from previous relationships had suffered greatly when a new male came into the mothers’ lives. In contrast, she held up Renato, who treated Ivar like his own son. This attitude she credited to Renato’s HIV status, saying his mother had “put it in his head” that, being HIV-positive, he could never have a child of his own. Milene thus portrays HIV as a causative agent in a positive sense, configuring the relationship between Renato and Ivar in a way that makes Renato a more desirable partner for her. This construction is a clear demonstration of the contingent and variable meanings that can attach to HIV and serodiscordance. Not only is Milene’s current evaluation of seropositivity at odds with hegemonic interpretations, it has changed over time, in response to events in her life.

Although, in this particular way, Milene constructs HIV as an enabling factor in her union with Renato, in other ways, the virus, and the couple’s serodiscordance, seems barely relevant to her. For example, during Milene’s first individual interview, she talked about the consequences of the couple becoming pregnant, saying, “the most that’s going to happen is, maybe we won’t be able to have sex, because [Renato] could transmit the virus to the baby, since I don’t have it. And if I get it, we’ll get treatment. Because there are various moms that have HIV and the children don’t, you know?” Her observation that Renato “gets all worked up” when her menstrual period is late prompted me to ask if he hopes for a pregnancy. Milene exclaimed, “Ah! He’s crazy to have [a child],” but then noted that she’d read on the package for Kaletra, one of Renato’s ARVs, that the drug can make “insemination” difficult. In addition, he’d had an “infection in his testicles” that they thought might impact his ability to father children. Milene said that she herself wanted to have a baby with him, but she wanted her health to improve first so she could be certain of her ability to care for an infant.
Nonetheless, two months later, it seemed the couple was taking steps toward becoming parents together. I arrived for a visit one week day, and was surprised to find both Renato and Milene at home. He had stayed home from work, partially due to a urology appointment scheduled for the late afternoon. Concerned, I asked if he was ok. He’d smiled and said, essentially, Yeah, fine—it’s just to check if everything is ok for the baby. Milene reminded me that no one knows the couple doesn’t use condoms and remarked that, for that reason, Renato’s mom is going to think the baby is someone else’s—especially if Milene herself doesn’t seroconvert during the gestation and the baby is also seronegative. What must be observed here is that, overall, the greatest constraints on the couple’s reproductive hopes seem to be Milene’s health and Renato’s mother’s disapproval. Biomedically, HIV is relevant to this situation primarily through possible side effects of a particular ARV, not in terms of any possible impact of the virus on Renato’s future, or Milene’s potential seroconversion.

The possibility of having a sexual relationship with Renato that did not entail exposure to HIV was discarded by Milene during her first formal interview. Male condoms were readily available for purchase at pharmacies and other retail outlets, as well as distributed for free (15 per month) at the clinic where Renato was a patient. According to Milene, however, Renato could not maintain an erection when wearing a male condom. When asked about female condoms, Milene made a face. Unlike most people I asked, she’d actually used a female condom; she’d sometimes obtained them from the HIV counseling and testing center when she worked there. She said she assumed they were still available (they were, and from the clinic as well), but complained that they did not permit much sensation. Availability of this difficult-to-find resource seemed not to be the issue.
Renato himself never acknowledged his problems with condom use to me; he glossed over the details of the couple’s first sexual encounter in his formal interview, conducted about a month after our first meeting. As he began to discuss the reasons behind the couple’s decision not to use condoms (the thread of which extends for several minutes), however, Renato’s entire demeanor changed. His voice, previously strong and lighthearted, dropped in volume; his answers were halting. Although he had told me previously that the decision to forego condom use was Milene’s, the explanation he offered here was considerably more ambiguous.

Renato: So [Milene] said, ‘If you don’t want to use them, don’t.’ I was scared about that, but I trusted in her confidence.
Shana: What were you scared about?
Renato: Of, of passing it to her…Even today, I’m scared to death [of that].

In this telling, Milene has left the decision up to Renato by not insisting on using condoms. He seems reluctant, however, to take responsibility for his choice not to use them, asserting that he is “scared to death” of the consequences. What I noted at the time was a profound degree of ambivalence on his part. This was a difficult conversation for Renato, whether because he was uncomfortable with the couple’s sexual practice or uncomfortable talking about it was not clear.

He continued, however, speaking more easily: “And thank God, it’s like she told you, she has a really open mind. She knows the risks she’s running…She loves me. This was one of the greatest proofs… She loves me. And so, this is proof.” In a dynamic potentially very similar to what Persson and Richards (2008) call “proxy negativity,” for Renato, who doubted he would ever find someone to “understand” him, Milene’s actions may serve as evidence that he has indeed achieved a “normal” life.

Milene had never spoken of her feelings for Renato as justifying her acceptance of the “risk” inherent in a sexual relationship with him. She had, in some sense, implied that exposure
to the virus could be “worth it,” either to satisfy her sexual desire, or as part of having a partner with whom she got along well, and who cared for her son as his own. The theme she came back to most frequently, however, in response to questions about seroconversion, was that it would be difficult for Renato to deal with, but pose little difficulty for her, apart from the ways it might complicate her already considerable physical problems:

Milene: Yeah, he’s going to feel guilty and things. Even though I tell him, ‘And if I get it? I’ll get treatment,’ I will, you know...
Shana: And it doesn’t worry you?
Milene: Mm, mm (negating).
Shana: Aside from your health problems, which is a really specific thing. If you get HIV?
Milene: No problem! Because they have all the medicines figured out and such—it’s like I said to him, ‘I get sick more often than you do!’

As is abundantly clear, given the data presented, this was Milene’s general attitude about HIV, and it was typically expressed in just this way. Supporting her emphatic “No problem!” however, is a justification that, while usually backgrounded (as it is above), is nevertheless fundamental to examine closely: the existence and availability of treatment for HIV/AIDS. As Milene made clear at a later interview, this was the basis upon which having a serodiscordant relationship was even conceivable. In discussing her understanding of HIV, she said:

Milene: For me, it’s not a seven-headed monster. I’m not going to say it’s a death sentence.
Shana: But if there was no treatment? Would the situation be different?
Milene: Oh, yes. If it was like it used to be, I’d be afraid, right? Because it used to be a death sentence—you just had to get pneumonia, some little thing, and poof! you were dead, you know? If it were like it used to be I couldn’t do it [i.e., be in a relationship with Renato]—when he told me what he told me [i.e., that he had HIV] I would have said, ‘Sorry, then, but good-bye to you’ and that would have been it.

Again, one is struck by the contingent nature of the meanings associated with the virus. Milene clearly posits a relationship between the availability of effective treatment and her willingness to engage in an intimate serodiscordant partnership, and, by extension, unprotected sex with her seropositive partner. Judgments of “acceptable risk” are clearly context-dependent.
I am not, of course, suggesting that Milene and Renato’s decision to forego condoms can be reduced, in a simple or direct way, to the availability of ARVs. Other factors are likely at play. Though Milene claimed pragmatic considerations as the predominant motivation for her actions, she’d also stated that her initial justification for unprotected sex was overwhelming sexual desire. Never addressed was the fact that, since being unable to work, Milene and Ivar were entirely financially dependent on Renato (although their sexual practices had been established prior to that period), who was under no legal obligation to provide for them. There was also Renato’s romantic interpretation of Milene’s decisions, and the possibility that not using condoms was an important embodied expression of “normality” for him. No single, satisfying story neatly encapsulated everything.

If anything, over time, the situation became murkier. Over two consecutive days of visiting after I’d known Milene for about two months, she commented in an off-hand way that female condoms would not be so bad to use—if Renato would ever bring them home. And two weeks later, after an interview that explored some of her past relationships, she sighed, musing that she had never been in love. About things like missing a man or thinking about him when he’s not around, she remarked, “All that waste of time, I never did.” Especially at an earlier point in her life, she noted that if a lover left her in the morning, she could find another one by that night. Explaining her relationship with Renato to me, she insisted that, although they had a good relationship, she wasn’t in love with him: I like him, like his company, we get along, things are good, but in love with him? No.

\[74\] Doing so, however, was immensely important to him. He said, “For me, it’s important that they lack nothing...When they do, I feel bad” (Pra mim, não pode faltar nada pra eles...Quando falta alguma coisa pra eles, eu fico mal), and further specified that this was not an attitude that came from his parents, but something that came from inside him.
After a few weeks’ break from the field, I returned to Porto Alegre in the dead of summer, when everyone with the means to do so escaped the city for the nearby coast. During this phase of the research, I was attempting to identify and recruit heterosexual, HIV-serodiscordant couples for another component of the project, which limited my ability to visit the couples I’d recruited for the sequential interviews. One day, as I scouted a potential focus group site, my cellular phone rang. It was Renato. His voice was anguished. I struggled, against the background noise and the onslaught of his words, to understand what he was telling me. Like fitting together the first few pieces of a puzzle, my confusion dissolved into an inkling of comprehension: Milene had been unfaithful. He had caught her. They had fought. One of them had left. He was so distraught, that was all I could understand.

There was no consoling him, but he said he would be alright. By the time I could call him back from a better locale, he was more in control, and we made plans for me to visit as soon as I could (several days later). When I arrived at the house, though, reconciliation was in full swing. Renato and Milene were all smiles, and more physically affectionate with each other than I had ever seen them before. I asked a few tentative questions about how they’d resolved the situation, and Renato’s face clouded. He said this would be hard to overcome, but they had decided to work it out. It was evident neither of them wanted to go into details. Indeed, I was not able to discuss this event in their relationship with either of them before leaving Porto Alegre. Some months after returning to the U.S., however, I opened my inbox to find an email message that appeared to be from Milene (although she had not had an email account during the couple’s participation in the study). It was quite short, asking if all was well with me, and sharing “news” that the sender had a “new baby.” Although I wrote back immediately, I never received a response.
Rita & Adriano

It was 2 September 2009, the day of Rita’s appointment with her HIV physician. It felt like a blind date. One of the staff at the clinic had mentioned that she knew of a patient who was eligible for my study, and about a week afterwards she confirmed that Rita and her partner were interested in participating; I could meet Rita when she came in for her next check-up. On the appointed day, I’d been observing check-in procedures, medication check-ups, and chatting with other patients in the waiting room, all the while scanning each new arrival in an attempt to guess which was Rita. She turned out to be a plump white woman, with a strong, straight nose and long, wavy brown hair. She had arrived shortly before her appointment because she’d come from work, and because she said she’d learned it did no good to arrive too early. Her doctor’s agenda was too full for any attempt to be seen ahead of schedule to be successful.

As a consequence, we didn’t have much time to talk. Though Rita was expecting me, her demeanor seemed guarded, and something about the concise, direct way she spoke was unnerving. Yet she was not unforthcoming. She told me that she had been diagnosed with HIV nine years previously, and had begun taking medication almost immediately. She had experienced one troca in that time because she simply couldn’t tolerate one of the drugs in her original regimen. This appointment was routine follow-up.

When I asked about her partner, Adriano, her responses were less clipped. They had been together for 15 or 16 months, although she said she strongly resisted the idea at first. He, however, was persistent. She linked her hesitation to fear of his possible reaction to her serostatus, but he took it well. She smiled the only real smile I saw from her that day when she told me that their plans for the future included marriage and children. She was called for her appointment, but we exchanged contact information and later set up an interview for the couple.
Both Rita and Adriano worked during the day, she as a kitchen aide at a daycare and he in the receiving department at a hospital. They lived with Rita’s mother on a lot where two of her sisters (along with their husbands and children) also had houses, but the couple was looking for a place of their own. Although most of Rita’s family members were aware of her serostatus, she told me she and Adriano could not be interviewed at their home (the standard practice for the other couples in my sample). Not knowing the part of the city where they lived, I was hard-pressed to come up with an alternate spot that would be private and quiet enough to conduct a recorded interview dealing with such intimate topics. I worried that having to travel—even a short distance—to meet me would become burdensome for the couple. I suggested a park, reasoning that many neighborhoods in the city have one. Rita reacted favorably to the idea but did not offer any options in her area. I raised the possibility of meeting at a well-known park a walkable distance from my apartment; I knew a busline that ran through her neighborhood stopped there. She readily agreed. It was only later that I realized how meeting outside of her part of the city minimized the chance of us being seen by people who knew her.

A few days prior to our scheduled interview, however, I heard from the clinic staff that Rita and Adriano had to cancel. When I reached Rita by phone to reschedule, I discovered that she and Adriano were at what is called “the biggest popular party in Rio Grande do Sul,” the Semana Farroupilha (described in Chapter 2). The background noise was overwhelming, but we managed to re-schedule our meeting, and she shared what I could tell—even through the din—was happy news: she was pregnant.

Three weeks later I finally met Rita and Adriano for their initial interview. We ate lunch near the park, then crossed the street and found a park bench, removed from the other visitors.

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75 Billed, on the event’s website (http://www.semanafarroupilha.com.br/index.php), as the “Maior Festa Popular do Rio Grande do Sul.” In this context, popular means “of the common people.” As mentioned previously, classe popular can usually be translated as “working class,” and is a similar use of the word.
who were largely sitting on blankets in the sun, drinking chimarrão in groups. Rita seemed more relaxed, and she sat near one end of the bench, leaving room for Adriano, who sometimes sat beside her and held her hand, but also frequently popped up, circled around, and squatted in front of us. This was the first time I had met him. His energy was palpable and he seemed in high spirits. He was slightly shorter than Rita, a trim Afro-Brazilian who appeared older than his partner—an visual impression soon forgotten, however, as one was inevitably caught up in the playful tide he created with his wide, easy smile and constant stream of jokes.

As far as I could ever discern, the couple’s habitual way of relating to each other revealed itself within the first five minutes of the interview. He teased her gently; she, feigning irritation, hid a smile, and they both ended up laughing. She acknowledged that sometimes her irritation was real and on those occasions his tendency to pay it little heed (literally, não dar bola or “not give [the] ball”) was frustrating. But, as she explained later during her individual interview, she considered herself frequently guilty of “talking without thinking first” and hurting people with her unflinching honesty. She also told me, about herself, “I’m an open book, because I can’t hide anything, you know? I’m very honest, I talk a lot and I tell the truth. I don’t lie.” I came, over the months I knew her, to conclude that her self-assessment was accurate. From the first day I met her, to the last time I saw her, it was easy to deduce how she was feeling. There was a brusqueness to her that I did not find to be common among other women I met in Porto Alegre, of any class or color. Rita acknowledged Adriano’s jokes and his “honeyed” way of talking were more conciliatory, and certainly a more accepted mode of communication. She saw the difference in their interpersonal styles as complimentary.

The trajectory of the couple’s past relationships differed as well. Rita was 35 years old, but had been in only two relationships prior to her involvement with Adriano. The first was what
she called a “girlhood romance;” it had lasted nine months but did not include a sexual relationship. Irate because she had seen this boyfriend with another girl, she had said to him, “‘I don’t want this anymore. Get out of here.’” She elaborated to me: “I felt so much rage. I hated him. I couldn’t stand to see him; I felt like going and hitting him.” Subsequently, at age 19, she began a relationship with a 33-year-old man who was perennially unfaithful to her. When I inquired about the contrast in her apparent tolerance for infidelity, she said, “I was in love with [the second one]. You know how love is blind?...How people told you things, and you didn’t believe them? How people saw and heard things and they told you and you didn’t believe them?... And your mom came to you and told you what she’d seen and you didn’t believe her?”

She said that over time her partner’s own behavior destroyed the love she had felt for him—and added that God may have answered her mother’s fervent prayers by finally showing Rita the man’s defects. She ended the relationship when they had been together six years. Rita had never been married, and had no children.

Adriano, on the other hand, had two ex-wives. The first was the mother of his 19-year old daughter; that marriage had lasted 13 years. They maintained a cordial relationship and were collaborating in the planning of their daughter’s upcoming wedding:

I’ve always gotten along really well with my ex-wife, with my daughter’s mom. She knows Rita; we even go over to visit her and things. But why is that? Because when our marriage was in crisis we sat down and talked, [saying]: let’s separate on good terms, we have a daughter. There’s no need for us to fight and break plates and each go our own ways and never speak again.

This was the wife Rita said she was physically similar to; both were larger white women. She claimed to have it on authority from a confidante of Adriano’s that he had never been unfaithful to his first wife, partly because she was his “type.” Adriano himself told me that his first marriage had foundered on the couple’s divergent sexual desires in terms of frequency, but
that he and Rita got along well in this regard: “I have no complaints about her; there’s nothing I want that I don’t have, especially sexually, so why would I look for a girlfriend?” He noted that his opposition to infidelity was not because he was incapable of such things; he had been unfaithful to a partner in the past, and would not lack for women with whom to have an affair, were he interested. But Rita’s dedication to him and knowing that she was faithful left him with no reason or desire to *pular a cerca* (literally, “jump the fence,” in Portuguese this slang means to be unfaithful to one’s partner). In addition, he described himself as a man who liked to be in a relationship: “I don’t know how to be alone. I’m needy.”

According to Rita, their histories made them “compatible.” She liked it that Adriano was sincere; he could be trusted to follow through on what he said he would do. She wanted a partner who would work alongside her, and she felt Adriano had demonstrated in his previous relationships that he understood commitment. She had no tolerance left for infidelity and saw him as unlikely to have an outside relationship. She also saw herself as having been much less serious, more playful, prior to her HIV diagnosis, and Adriano reminded her of that. Both partners came from larger families with whom they had close ties. Both described themselves as having strong Catholic faith.

They had met at a church dinner and dance where, according to Rita, Adriano had initially been interested in a friend of hers. He, on the other hand, emphasized that he was in the process of ending his previous relationship and had been looking for someone with a happy, playful nature. It hadn’t taken him long to deduce that Rita fit the bill. He added: “Another thing that I liked about her and that I like to this day is that she’s plump. I really like plump women.” When he asked her to dance, however, she told him she did not know how, hoping to put him off. He, unperturbed, said he would teach her. Rita says, “And so I went and danced
with him and afterwards he said, ‘Ah, so you were fibbing about not knowing how to dance, huh? You do know how and you were keeping that under the rug!’” He asked for her phone number that first time they met.

Ahead of a subsequent dinner and dance at the same church, a friend of Rita’s who had been along on the first outing told her Adriano had called to inquire whether the girls would attend, which they did. She said she spent much of the time fleeing from him: “I hid under the tables…I stayed sort of hidden, I kept my head down so he couldn’t find me. But he did and took me out to dance.” Not only that, but they left the building to get some air and talk; most of the conversation turned out to be about Adriano’s desire to kiss Rita. As Adriano narrated: “That first time, she was saying, ‘No, no, no’ and I was asking, ‘Why, why?’ And it went on and on like that...We kissed a little, did some petting, just things like that.”

It’s worth noting that this sequence of events adheres closely to mainstream expectations of the roles for men and women in initial stages of a romantic relationship. Rita declines Adriano’s initial invitation to dance, he insists. She hides, he finds her. She resists his physical advances, he persists. In contrast to Adriano’s fundamentally active approach, Rita is passive or eventually submissive (of course, this is too neat a distinction; she did dance with him, attend the second event cognizant of his likely presence, and go outside in his company, all of which demonstrate her agency and, to Adriano, her interest in him).

In his narration of their first physically intimate encounter, Adriano notes, “But that time we just ficou.” The verb ficar in Portuguese can mean many things: to stay, to be located somewhere, to become or acquire some particular attitude or characteristic, and to agree on something, but it also means to casually engage in some sort of physically intimate act. It can include everything from, for example, kissing someone at a party to leaving the party with that
person with the express purpose of having casual sex. In this sense it is roughly equivalent to “hook up” in English. At least among people in their mid-thirties and younger, *ficar* has become institutionalized as a particular type of relationship. One can even be a *ficante*, or someone with whom another person has this type of no-strings-attached relationship. In this instance, when Adriano says the couple just “ficou,” he’s communicating that there was no expectation on either partner’s part of a tie beyond that particular interaction.

Later that week, however, Adriano called Rita to invite her out. In the course of the evening, he asked her to be his girlfriend and she refused, claiming—as she noted she had told him from the beginning—that she did not want any sort of commitment.\textsuperscript{76} He, feeling sure there was more to her reasoning than she let on, insisting on knowing why. He told me during the couple’s joint interview, “I thought there were two possibilities. Since we know that the world, in general, is prejudiced, first I thought it was because I’m black, and second because she’s overweight. Those are two prejudices that are very common here.” He hounded her for the rest of the date about her refusal, never suspecting Rita had HIV.

For her part, Rita clearly portrayed herself as having been in disbelief about the events that were transpiring, if not unreservedly terrified. But her assertion of shock at his proposal struck me as incongruous. As noted, both Rita and Adriano had been admirable performers of normative gendered expectations about how conjugal relationships form. It was only later, through narratives she offered in the joint interview as well as her individual interview, that I

\textsuperscript{76} Adriano was likely truly puzzled by this response. In one sense, it maintains the gate-keeping role assigned to the woman, he may have felt that further insistence would get him what he wanted (as, indeed, it did in the end, although surely not in the way he imagined). But the reason Rita offered for not accepting his offer of namoro deviates from the gendered script the dyad had adhered to up to this point in an essential way. Men are imagined as driven by their desire for sex; women are understood to want a relationship. This is exactly what he was offering her, and she had refused!
came to understand how deeply and fundamentally Rita’s HIV diagnosis had altered her perception of herself and her dreams for the future.

Rita’s diagnosis was essentially accidental. She had accompanied one of her sisters, who wanted to be screened, to the testing center as a favor. At that time HIV testing at this facility was anonymous, and the required pre-test counseling was done collectively, as a talk given to the group of individuals present to be tested. The sisters and at least one other individual had received the pre-test counseling together; the blood draw was, of course, individual. Rita’s sister had gone alone to pick up her results when they were ready; she was HIV negative. As the story goes, she somehow saw her own results (identified only by the number she had chosen) on a list that included others, which she assumed corresponded to the people who had been tested on the same day she had been. Her own “not reactive” was sandwiched between two “reactive” results. Thinking back, Rita’s sister remembered the order in which those wishing to be tested had their blood drawn. She rushed home and told her mother that she thought Rita might be HIV positive.

She did not, however, tell her sister. According to Rita, her mother began pestering her about picking up her test results until she gave in, saying, “Ok, I’m going, get off my back!” As Rita recounts what happened next, particular details are fuzzy. She gives a bare-bones rendering of the sequence of events, emotionally barren except for a suggestion of mockery she creates by exaggerating the already sing-song accent of the *Gaúchos*, placing extremely heavy stress on some words (bolded below):

Rita: One day I went. I went in the afternoon, I think. I think it was the afternoon. Yeah, I went in the afternoon. I went there, one day—I don’t know what day it was. So I went there, I got a little paper and everything, and went up, ‘I’d like to see my results,’ you know? …and then [a woman who worked at the testing center] saw about it, got the number, typed it into the computer and then went and got a folder and then she started to explain, explain, (more quickly, emphasizing the repetition) to talk and talk and talk and talk—

Shana: Was this individual—
Rita: Individual.
Shana: In a room, just the two of you?
Rita: Just me and her. Just me and the doctor, right? And her explaining all about AIDS. And… what it’s like, and so on, and so on, and so on. If, if, if—how it was that I was feeling, and all that, you know? And then, for her to finally get to the situation that I was seropositive, and all that (sighs)—it was like a book! Why? Because they prepare the person to get the news, you know? They talk, they explain, right? About HIV, all that stuff, right? And all that for her to tell me…Yeah, when she told me, it was a shock, ok? I started to cry, cry, cry, and cry, cry. She went and got some water (laughs a bit) for me so I could calm down. Then I went home and told them.

The diagnosis was devastating for Rita. At 26, she was single, having recently ended the long-term relationship that had been deeply hurtful to her. She said she thought of all the ways she could kill herself. It was a deep depression that lasted about two months. She credits her family with helping her get over that period. As time went on, more family members learned of her serostatus, including most of her brothers-in-law, whose reaction she had feared. But their treatment of her did not change.

And yet everything had changed for Rita. She spoke several times during our interviews of living in “[her] own little world” after her HIV diagnosis. I asked her what that world was like:

In my own little world…I got home from work, I shut myself in my room. I didn’t come out of there except to eat, shower. I slept, I got up in the morning and I went to work. That was it. That was my little world…Oh, my mom got worried, my sisters, and all that. Because I stayed locked away, I didn’t live. I had no life.

She eventually sought psychological help, and the clinician she worked with on an individual basis at the counseling and testing center pushed her to open back up to life, to contemplate the possibility of a man becoming interested in her. With time Rita’s seclusion did lessen (she, for example, allowed her friends to prevail upon her to attend events like the dinner and dance at their church), but neither she nor her family thought the latter eventuality would ever come to pass. She felt afraid of her own body, and of potential rejection from other people.
She names these as factors that contributed to a “block” in her mind that didn’t even allow her to consider a future with a partner, but there was another influence as well:

The truth about this block that I had about my illness is that I was afraid of passing it to someone else. You know? This block about not expanding my horizons any more, not being interested in another man, right? This left me in my own little world, closed off and afraid. So when [Adriano] asked me to be his girlfriend, I was really scared… Look…I know what it feels like to discover [that one has HIV], ok? And I didn’t want that for anyone. No way, because I went through that myself… Nowadays I can have a conversation, I can talk about the illness. Before, whenever I talked about it, I cried; I couldn’t even speak.

Returning, then, to Adriano, given this history Rita’s shock when he asked her to be his girlfriend becomes more comprehensible. In essence, he had, in the space of a week, demonstrated the unthinkable: that a man could be interested in her, and would offer the very thing she had closed herself off from the world to avoid wanting. By not taking no for an answer, he was pushing her to confront that which she feared most: rejection as a result of her seropositive status. She thought to herself:

Oh, my God, oh my God, let it be as God wills. And I just told him...And then I waited, you know? But I was waiting for one thing and what happened was the opposite… Because he came back with, ‘What I feel for you doesn’t change because of what you have.’ I was frightened because I didn’t expect that. Still I said, ‘Well, alright then.”

Adriano went the next day to talk with a nurse, to get answers to all his questions about sex and relationships in the context of HIV. The nurse asked him, “Do you think you really want to be with her?” “I do,” he replied.

The decisions this couple made about their relationship were not made from a position of ignorance about HIV. Both Rita and Adriano separately explained in their own words multiple ways HIV can be transmitted and how transmission can be avoided, in accordance with the basic biomedical model. They also both stated that women are more easily infected by men than men
are by women. However, neither was aware of the differential likelihood of transmission by sexual practice (oral vs. vaginal vs. anal sex, for example).

More interesting than any attempt to measure their knowledge about epidemiological probabilities, though, was the way the couple’s responses diverged when asked, “Are there people who are more at risk of getting HIV than other people?” For Rita, the question seemed to conjure “different kinds” of people. She said, “Of course not, you know? Because getting a disease isn’t exactly like that,” thereby implicitly rejecting historical “risk groups” in favor of a notion of “universal vulnerability.” She went on to talk at length about persistent popular misconceptions about HIV transmission, and to emphasize the need to educate the public and eliminate discrimination. Rita interprets the question in a way that allows her to minimize the difference between seropositive individuals and the rest of the populace, and to talk generally about stigma.

Adriano, on the other hand, answered the same question, focusing on “immunity” as a factor that separates individuals who more easily and quickly contract HIV from those who don’t:

Adriano: I think so, because people are different from each other...There are people who have a low immunity, although it doesn’t show up, they don’t know it. The have really low immunity and they’re more likely to get [HIV] quickly. But I think I have high immunity, you know?
Shana: It seems that way, doesn’t it? (laughs)
Adriano: No, but really! Because, look, sometimes I am impressed with myself. How is it that I don’t have it?

Adriano’s response, like Rita’s, elides any possibility of talking about “risk groups,” but, unlike his partner, he eschews any discourse that emphasizes similarity. Instead, he hypothesizes internal, unseen differences in immune response even among uninfected people. In addition, he quickly personalizes his response, characterizing his own body’s response as “impressive.” Rita and Adriano’s answers to this question should be seen not only as indicative of their
understandings of risk, but also as a venue for them to deal with current personal concerns related to HIV.

As my exchange with Adriano related above suggests, the couple was not consistent in their use of condoms. In my first conversation with them about this topic, I noted that if they had been trying to conceive, then they must have dispensed with condom use, but Rita corrected me. The doctor had given her a couple of syringes and instructed her in how to use them to extract the semen from a used condom and inject it into her vagina. Her tone was so matter of fact it seemed possible they had actually followed these instructions. I asked in disbelief:

Shana: Is that how you did it?
Adriano: (quickly and dismissively) No. (laughs)
Rita: (immediately echoing Adriano): No.
Shana: Obviously not, right? No one is going to do it like that.
Adriano: But that’s what he wanted us to do. The doctor—(here Adriano can no longer keep a straight face; Rita and I burst out laughing at his expression and he follows suit)...That would practically be an artificial insemination.

Although he did not explain why, Adriano’s tone left no doubt that artificial insemination was undesirable (as mentioned in Chapter 3, other serodiscordant couples also have negative perceptions of assisted reproduction techniques: Ngure et al. 2012:514). The fact was, though, that the couple had not been using condoms consistently even prior to deciding to conceive a child. As Rita explained to me that afternoon, “He’s in a hurry, he doesn’t know how to wait.” All three of us began to laugh as she insisted, “He just can’t wait; he’s out of his head!” Adriano agreed with her assessment, looking proud and amused. He noted that the gynecologist at the HIV clinic had sent him to do bloodwork for HIV, Hepatitis, and other problems as a result of Rita’s pregnancy, but he received a clean bill of health. I asked if that led them to any conclusions about their condom use habits. Their answers showed a clear difference of opinion:

Rita: That we shouldn’t do what we do [i.e., not use condoms].
Adriano: That we’re going to keep doing it! (in a light-hearted tone)
R: **Not** to keep doing it.
A: It’s the opposite, we are going to keep doing it. I didn’t get [HIV]!

(he laughs)

R: (half laughing) But to me that thinking is wrong. You didn’t get it and then in the future [without a change in habits] you will.
A: (suddenly quite serious) I don’t know, I stop to think and lots of times it just clicks that it seems that (choosing his words slowly, deliberately) my love for her, our love as it were, is greater than this. Given the times we’ve already done it without a condom, I should already have gotten it, you know? Sometimes I get to thinking, it seems like this love, my way of being with her without worrying about it, it seems like it’s delaying the transmission, you see? So I’m not worried about it. I’m really not. Sometimes we’re together for a little bit, at the beginning, without a condom and when (returning to light-hearted tone he used before) things start to heat up we say, ‘Let’s put one on, just in case.’ (laughs) It could just be stupidity on my part, because it’s too late, in quotation marks, but still. At least I used one (laughs)...It’s a little like that.”

This was not a laughing matter for Rita, though, which I remarked on at the time. She said, “He’s always joked around like this, since the beginning [of the relationship]. I’m more serious, you know, I worry more because this thing is mine. It’s inside of me.” Adriano immediately acknowledged the validity of her feelings but just as quickly returned a sense of levity to the conversation that made both Rita and I laugh. Having made a mental note of this exchange, I asked her about it when we were alone. She said:

“It’s that we’re just very different...Because I know what I went through...when I say something seriously, it’s serious. You know? There are things that I just can’t joke about. I suffered a lot to (pause) oh, to get through what happened to me. To accept it all, to get my life back to what it was before, you know?

She worried principally about two issues. She wondered whether Adriano, would “subconsciously,” blame her if he seroconverted. She also feared the reaction of some of Adriano’s family members. Both of his parents were deceased, but the siblings were very close. They were unaware of Rita’s serostatus, so if he became infected, she imagined a double disclosure, with potentially catastrophic consequences: “Just imagine what it would be if the family distanced itself because of me. I don’t want that, because they’re his brothers...What I
want [Adriano] to understand is that I don’t want his family to withdraw from him. Because family is important.”

Family was an important part of Adriano’s life; he played soccer with a group of his family members every week, and frequently went with them to the stadium to watch matches. They were also integral, however, to what he stated as one of his week’s greatest worries during the couple’s joint interview: what would the couple say when his family asked why Rita did not breastfeed? In general, he deflected discussion about why none of them knew about Rita’s serostatus by saying, “I’m old enough to have my problems and keep them to myself, to resolve them myself,” but he knew sooner or later someone would ask. Rita clearly had assumed they would answer with something other than the truth, but Adriano seemed undecided:

Adriano: When it comes time and someone asks me, I may just tell the truth. I’ll tell the truth and admit it/take it on.
Rita: My worry is that your family is prejudiced.
Adriano: Yes, but everyone has prejudice; there’s nothing to be done about that. It’s for that and other reasons that I haven’t said anything up to now. I’m not planning on telling them, but it’s the kind of thing you say when the time is right.

Rita worried that Adriano had not thought this through. If he had not spent much time mulling it over, however, that wouldn’t have necessarily been a departure from the way he dealt with the issue of their serodiscordance in general, at least as he explained it to me. In his individual interview, after marveling at his own immunity, he returned, at my prompting, to theorizing about his continued seronegativity:

I attribute it to just one thing, one person...Because I’m very Catholic, my whole family is Catholic, I attribute this to God. I think that my love for her is what prevents me from getting [HIV]. It protects me because I’m not prejudiced, I’m with her to this day. It didn’t phase me when she told me she had the virus. So that’s the only way I’ve explained it.

God’s will may have been the ultimate explanation, but it was not, in fact the only one Adriano offered. He continued:
And another thing: I don’t get fixated on it [literally, “I don’t keep putting it in my head”]. Maybe the psychological aspect [i.e., thinking about becoming infected] makes you more likely to catch things. So I do what I do and I don’t worry. Well, I mean, I don’t worry too much. You have to worry, but not to the point that you keep thinking about it, and I can’t do this, and I can’t do that…

This was largely the same approach he took to his health in other aspects. Although he was very healthy at the time I knew him, he noted that most of his siblings had heart problems. This was to be expected, since, at his estimate, 70 or 80% of his family—himself included—had Chagas Disease. He had lost his mother and an older brother to complications of the disease already, and anticipated developing similar issues himself as he got older.

Refraining from worry, however, did not mean that Adriano did not plan for the future. The first piece of news he shared with me when we met, in mid-December 2009, for his individual interview, was that he and Rita had bought a house. Her family had been integral in helping them find it, but his financial planning had been sufficient to afford not only the house and new appliances, but also to cover several small improvement projects the couple wanted to complete soon after moving. The baby’s room, for example, was a pressing concern. He also noted that with this squared away, he was thinking more about his professional future, and had decided to enroll in a specialization course in his field. The classes would begin in several months.

Happily, upon my return to Porto Alegre I was able to visit the couple at their new home. I took a bus most of the way, but Rita had to pick me up from the stop closest to the turn-off from the main road that led to their house. We bounced along unpaved roads in the couple’s car for a while, arriving at their residence to discover that Adriano had prepared a traditional

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77 Adriano noted that his family is from “o interior,” meaning a rural part of the state. Chagas disease, a parasitic infection that often affects the heart (see http://www.cdc.gov/parasites/chagas/disease.html), is common in rural Rio Grande do Sul.
churrasco (the barbeque of Southern Brazil). I was given a tour as soon as I arrived. In the 
baby’s room, brand new furniture stood ready to welcome its future occupant, whose birth was 
still two months away. The other rooms were sparsely, but not spartanly, furnished, with the 
kitchen having received the most obvious care. The couple seemed happy, and quite at home, 
although the summer heat was making very-pregnant Rita uncomfortable. Just prior to 
beginning an interview, a carload of her family members unexpectedly appeared. They lived not 
far away, and this seemed to be a common occurrence. I was introduced as a friend Rita had met 
during a pre-natal visit. Beers were passed around (with Rita abstaining), the talk turned to 
soccer and babies, and it was soon all I could do to keep up with the jocular flow of 
conversation. The last time I saw Rita before I left the field, she proudly showed me the couple’s 
newborn son, whom she had brought to the new installations of the clinic for his specialized 
follow-up appointment. He was, as far as anyone could tell, healthy.

Bibiana & Felipe

The day after I met Rita, I was back in the clinic, observing consultations with the nurses 
when Tina, one of the advanced interns, called me over. She had discovered the patient she was 
attending was eligible for the study, and wanted to introduce us. Bibiana was a slender, bubbly 
brunette with a brilliant smile, who readily accepted my presence. After Tina concluded the 
appointment she stepped out, giving us the exam room for a short chat.

Bibiana seemed completely at ease, friendly and extremely forthcoming. She was 33 
years old, and worked as a sales representative. This was not surprising since, being white, able-
bodied, youthful and attractive, she was the very definition of boa aparência (literally, “good 
appearance”), a common qualification for employment in such positions. She had been 
diagnosed with HIV in April of 2008, but had disclosed this to virtually no one. Her current
partner, Felipe, and her ex-husband, however, both knew; they had been tested and were seronegative.

Given what I perceived as concern with maintaining the secrecy of her diagnosis, we talked about possible consequences of the couple’s participation in the study. My fieldnotes about our conversation (recorded immediately after she left) include the statement, “She’s just a bit uneasy about having [Felipe] talk to me because ‘notei que algumas coisas já mudaram’” (Bibiana speaking: I noticed that some things had changed). This served as a launching point for her to talk about the couple’s sexual relationship. Specifically, she shared that it had become extremely rare, since her diagnosis, for them to have oral sex. Explaining further, she said, “A block was created: I don’t ask him about it and he doesn’t bring it up.” Yet in the next breath she recounted a tense interaction they had had about precisely this issue. Watching television together, a sex act they no longer engaged in—she couldn’t remember specifically which one—was mentioned. She remarked to him, “If I want to do that I’m going to have to hire someone from outside to do it, huh?” He had answered, “But you never were very into that. Not even before.” She admitted that was true but added, “That could change. Someday I may decide that it’s fundamental.” “Oh, yeah?” he had retorted, “and who are you going to get?” “Oh, no one—someone else, right?” she concluded. “Ah, you let me know when that happens then,” was his response. She smiled at me, appearing to minimize the gravity of what she had just revealed by contextualizing it: “You know, a lovers’ spat.”

She turned to talking about her diagnosis with HIV. Bibiana had not specifically sought out testing. She had not felt ill or suffered from any opportunistic infections. She was diagnosed with the virus as a result of routine pre-natal screening conducted in Porto Alegre. At the time, she and Felipe had been officially together for about a year and she was happily carrying his
child. Her voice full of pathos, she recollected how one day she had been in the midst of all the early prenatal bustle; three days after that, she was no longer pregnant. The couple had decided to abort the fetus, although abortion is illegal in Brazil. Everything had happened so fast. She said, “You know, we didn’t know anything. I thought the baby would have [HIV], that I was going to die and leave a small child, plus the one I already had” (Bibiana has a daughter from a previous relationship).

She clearly felt sad about this outcome of her diagnosis, but she also constructed the lack of children from this union as problematic for Felipe’s family. Felipe was his parents’ only son, and they seemed to want grandchildren very much. She perceived their frustration this way: “First you get together with a woman who already has a child and then she doesn’t want to have any more?!” Felipe’s family, though, was unaware of Bibiana’s HIV status, and, I discovered later, had not even met her—not a typical in-law relationship. Felipe, though, had dismissed her concerns, noting that he loved Bibiana’s daughter, Janaina. She was enough; they would raise her together.

The issue did not seem so neatly settled for her, however—nor should that be surprising, in light of the importance of children in solidifying sexual-affective partnerships in Brazil (Santos, et al. 1998; Paiva et al. 2003:94; Knauth 1997b; Ford et al. 2003). That day, as well as during each and every one of our subsequent meetings, she commented on all the HIV-positive expectant mothers that were patients at the clinic. She had discovered (and this was openly discussed among patients and staff alike) that many of these obstetric patients had seronegative partners with whom they had multiple children, and high-tech interventions like sperm washing and artificial insemination were rarely involved. Bibiana said then, as she did frequently over the months I knew her, “Como é que pode?” (literally, How can it be done? Or How can they do
that?). I was never certain whether this question arose out of disbelief that couples would repeatedly engage in unprotected intercourse, or whether she secretly wondered how she might convince her own partner to do the same.

It had been my understanding that Bibiana was worried Felipe might be uncomfortable with the study because their sexual practice was a touchy, if not taboo, subject. Therefore, I wondered whether he would consent to participate. But less than three weeks after I first met Bibiana, I was on a bus, heading to the southern part of the city where the couple lived. I had explained that during this first visit to their home I hoped to complete their joint interview. Bibiana had remarked that the day we had chosen would be perfect, since Janaína would be away.

As I descended the bus at the appointed stop, Bibiana was there waiting for me in the couple’s car. Getting to the house was a bit tricky, so the idea was for her to show me the way the first time. In truth though, I never did learn the route; she always came to get me and began talking as soon as we laid eyes on each other. After a few minutes’ drive, she pulled up to a substantial gate and announced we had arrived. We entered and I found myself in a large enclosure with three houses. Bibiana parked the car next to a two-story residence and we went inside.

The floorplan was airy and open on the ground floor. The tile floor gleamed throughout and sunlight streamed in the many windows, reflecting off the white walls. One entered the living room and could proceed through to the dining area. The kitchen was separated from these spaces by a wall and an island. Continuing through the dining area, with its large table and six chairs, through the back door one could see a private patio, painted a cheery yellow and complete
with a permanent barbeque grill. Upstairs, the master suite had its own bathroom and walk-in closet. Janaína had her own room, as well as fairly uncontested run of the bathroom on the hall. In addition to framed pictures, there were several large pieces of poster board on the walls downstairs, each featuring photos of Felipe, Bibiana, and Janaína. Bibiana described each depicted outing in turn, noting how much she loved photographs. Pride of place was awarded the shots of Janaína’s birthday party, taken just a few months before. Elated and beautiful, the eight-year-old shared the frame with other happy children and elaborate decorations.

Felipe was waiting for us, and for lunch. He was tall, standing head and shoulders above Bibiana. He was slightly overweight, with very pale skin and dark brown hair. His eyes were also dark brown, and set in a face that, at 32, still had a boyish charm to it. His smile was amiable and genuine. Bibiana remarked when she and I were alone, “He didn’t use to be that size; he’s fat now, but you look at his face and he isn’t ugly. He’s quite handsome, you know?”

The three of us chatted while Bibiana finished getting lunch ready. Her physician had given an interview on a popular television program that morning, but, without a TV, I had missed it. Bibiana and Felipe had as well, but she had watched it online and began peppering me with questions about the research study her doctor had discussed.

Just before lunch, Bibiana brought her neighbor’s two-year-old son in to eat with us. She and Felipe joked that they had adopted him, the boy spent so much time in their house. After clearing away the dishes, however, instead of settling down to the planned interview, Bibiana decided to take a shower and give the boy a bath, surprising both her husband and me. She absconded upstairs, leaving a visibly uncomfortable Felipe to be interviewed on his own. Thinking back to my first meeting with her, I wondered if she felt uneasy regarding their joint participation in what she anticipated to be a potentially difficult conversation, and if her
disappearance was intended to postpone this interaction. Thinking there would be other opportunities, I did not insist on speaking to them together. Neither did I press Felipe beyond what the limited rapport we had been able to develop to that point seemed likely to sustain.

We talked first about work—a subject unlikely to make any gainfully-employed Brazilian male uncomfortable. Felipe worked in the specialized manufacture of dental prosthetics. He had studied civil engineering (briefly) and three years of veterinary medicine at a university, but said he “didn’t see much future” in that field. Felipe’s father was a dentist, so, in order to begin earning his own money, Felipe completed a two-year dental technician course and started making the pieces his father’s patients needed. His father had purchased all the equipment for him, and they set up the workshop in an upper class neighborhood, on one of Porto Alegre’s most high-brow streets.

Although his work was highly skilled, Felipe did not earn a salary. Instead he was paid by the piece. He described their economic situation prior to Bibiana obtaining employment, six months earlier, as somewhat difficult, but it had since become “a bit more comfortable […] We have good things here at home, we don’t do without.” Such an assessment made sense coming from someone raised in an upper class Brazilian family; to me, having spent time in the rougher neighborhoods and much humbler homes of several other participants, it felt like the product of incredible, unconscious privilege.

Seated on the couch, with me ensconced in an adjacent loveseat, Felipe seemed nervous. He fidgeted. His sentences, in the first half of the interview, frequently trailed off. Nonetheless, he was good-natured and, as he warmed up, clearly had much to say. After discussing his professional training and household economics, I tried to move our conversation into more personal, but still comfortable, territory by asking about he and Bibiana’s history. He said they
had known each other for seven or eight years, but had been together for only the last two and a half: “Deciding to get together was something that came on naturally.... It was something that carried us, along with the course of events.” Not understanding, I attempted to clarify:

Shana: But, I meant, was she your friend before? Were you friends?
Felipe: Yes.
Shana: And then the relationship changed, right?
Felipe: Yes.
Shana: How did it change? What happened?
Felipe: I think it was a lot of complicity, involvement, you know? A lot…It went transforming like that…we were really… We kept getting to know each other better, more intimately. We kept spending more time together, had more in common. It was a really natural thing for me, you know? I felt that I wanted to talk, wanted to be with her. We missed each other. We started realizing. It was...it was really gradual like that.

Without discounting the influence of the circumstances of the interview (i.e., being interviewed alone, about sensitive topics, by a woman he had known all of two hours), Felipe’s evasiveness nonetheless seemed purposeful,\textsuperscript{78} and we moved on to other topics.

What Felipe discussed more easily, and at length, was receiving Bibiana’s diagnosis, his actions resulting from that turn of events, and the day-to-day work of managing the infection. He was the one who had picked up the results of the pre-natal screening, since the test had been done by a private (i.e., not part of SUS) laboratory that was on his way home from work. He remarked that he remembered the day exactly: the 23\textsuperscript{rd} of April 2008.

I looked and the result was positive, you know, for antibodies and whatever. I went to talk with the woman [who worked at the lab] and she [said], “No, we can only talk to the person about the results. We can’t discuss it.” And I [said], “But I saw something about a confirmatory test, right? There’s another test to do...to confirm.” And she [said], “No, everyone gets that.”

\textsuperscript{78} There was, indeed, more going on here than I was aware of at the time, which will be discussed below.
Confused, he called a close friend who, while not a doctor, worked at a health post and dealt with HIV frequently. The friend was able to explain what was written on the paper, confirming that Bibiana had tested positive for HIV. He talked to Felipe about the availability and effectiveness of ARV treatment, impressing upon him that “nowadays…things are different. It’s not like it was before, when it was a [death] sentence and everything. Things had changed.”

This friend, however, also cautioned Felipe about the future of the unborn child, saying it was “complicated,” despite what people claim regarding the prevention of vertical transmission.

Felipe explained, “They say 97%... [my friend] told me ‘Look, they say that number but it’s not exactly like that. After this happens and you’re going to give them…’ It’s a difficult thing, you know?

It’s unclear whether the ambiguities and ellipses in this story derive from Felipe’s reluctance to put this difficult period into words, his misunderstanding of what his friend intended to communicate, or incomplete knowledge on the part of his friend. He, later in the interview, claimed he had already “known” that HIV-positive individuals “couldn’t have children.” But established standards of care for preventing MTCT are highly effective, as has been demonstrated even in Porto Alegre’s public health services (Kreitchmann et al. 2004, Breno Riegel Santos, MD, personal communication). Effectiveness is contingent, of course, upon adherence, and it is possible that Felipe’s friend had personal experience with cases of HIV-positive pregnant women who did not or could not implement their treatment as it had been prescribed (which would have influenced his perception of its effectiveness). Whatever the case, this bit of information proved decisive in the deliberations that followed. The couple decided to abort the baby. I asked Felipe how he and Bibiana had come to that decision:

We saw that it wasn’t our right to play with another life, you know? How terrible, for [the baby] to arrive with this already, right? It’s one thing for you to discover, at thirty-something, that you have it and carry
on with the rest of your life—but being born with it? That’s more complicated. And she understood—I didn’t even need to... It was difficult for me, too. [...] A part of me wanted to try, to risk it. But I thought about the horrible things that he would have if... But it was one of the worst situations of my life, I think.

This was one of the only times Felipe admitted having a negative emotional reaction to Bibiana’s diagnosis, or the events that followed. He also acknowledged he had felt “a bit nervous” before he was tested for HIV the first time (the day after the couple received Bibiana’s results), and described himself as being “calmed” by his friend immediately after visiting the lab. But in each of the other thirteen times he mentioned his emotions during the course of the interview, it was essentially to deny he had any, saying he experienced a “block,” or was “blinded.” Instead, he emphasizes his concern with helping Bibiana assimilate the news:

Look, in the moment [...] there’s so much adrenaline that you can’t—you don’t get desperate, you don’t break down...you want to deal with things and something comes over you...It’s like I told you, I had this block that I just wanted to tell her...I didn’t even think about myself. I’d been with her for a year. If she had it, then of course I did too. But in that moment I didn’t think about myself. I just wanted to tell her in the best way possible.

The couple was not living together at the time of the diagnosis, and Felipe asked Bibiana to come over to his apartment to talk about her results. He said, “And from that it was the whole night, you know? Horrific.” Her first reaction, according to Felipe, was fear for the baby. He had given her a sedative. I asked him where he drew the strength for this, and he answered:

I saw that the situation wasn’t about me. I thought to myself that...that I just had to help. The grave situation wasn’t actually with me. I didn’t feel I had the right, you know, to lament and be weak [about what had happened]. I felt obligated to make things work as well as possible. And that’s...that’s where I got the strength.

Without belaboring the point, it is worth noting that Felipe’s reported reaction to this series of events exemplifies the gender-specific dictates of strength and stoicism for men (Ford et al. 2003; Knauth 2007).
His desire to “make things work as well as possible” continues to the present. Bibiana began taking ARVs in January of 2009, and her current pharmaceutical regimen requires her to take one pill at noon and two at midnight. Felipe said he often reminds her to take her medicine, even bringing it to her when they are at home. He smiled in spite of his frustration as he told me, “Sometimes I help so much that she gets irritated and yells at me, when I want to control the situation too much.” Bibiana noted that he calls her every day at noon to ask her if she’s taken her pill yet. She does at times find this annoying because, “I’m not one of those crazy people that don’t want to take it. [Felipe] does this just to remind me, in case I forget, but it’s usually not necessary…I tell him, ‘You don’t even ask how I am, all you think about is whether I took my medicine!’” Although I spent comparatively little time with Felipe, on the occasions I was in his company, he did not give the impression of being overtly controlling. He was typically happy to have a beer, watch soccer, play with the kids, and chat, whether at home or a restaurant.

In December of 2009, when Bibiana had been on ARVs for nearly a year, she recounted the story of the most recent of the three occasions on which she had missed a dose. The couple had traveled to a neighboring city, and she had miscalculated the number of pills she needed to bring. She realized at the bus station that it had slipped her mind to take a pill before leaving the house, which meant she would be one pill short over the course of the weekend. When Felipe discovered that she would miss her regular dose on Sunday at noon, he wanted to cut the trip short and return home as soon as possible. She refused: “Oh, go fly a kite! I’m not going to die if I forget for one day, you know? [...] It’s not like if I don’t take the medicine every twelve hours exactly I’m going to get something. And I have to explain that to him sometimes.” Their differing approaches to medication also come to the fore in terms of prescription refills. Felipe complained to me that Bibiana sometimes takes her last pill before she goes to the clinic to get
her next month’s supply. This makes him uncomfortable: “I tell her, ‘Damn it! Sometimes it seems like the partner suffers more than the person who actually has the problem,’ and she gets mad.”

If part of Felipe’s suffering was resigning himself to his conviction that having children of his own with Bibiana would entail taking an inadmissible risk, he did not let on. He acknowledged that he had wanted kids, but insisted that upon receiving news like an HIV diagnosis, “you forget these whims you’ve had, dreams of having my own children…you worry about [helping your partner].” It seemed he had developed an understanding of the situation as a whole that lent purpose to the couple’s loss:

Felipe: It’s rough to go out into the underworld, looking for a butcher to dispose of the child.
Shana: Yes. How did you find someone? Is it difficult?
Felipe: We found...A friend of [Bibiana’s] found him. She had done it [i.e., had an abortion] and told us the name of the doctor there. It even happened that, like, a month afterward, there was a blitz and they arrested the guy.79 But it all worked out just right, you know? It seems that she got pregnant in order to find out [about her serostatus], and we went [to that doctor] at the right time. That’s what I think anyway; that was the mission of the baby we were going to have. It was at least to let us know early, you know? [Bibiana] was never sick. She started the treatment...her [CD4 count] was good and everything, but when it started to dip a little bit she started to take the medicine and it came back.

The child the couple had wanted, then—at least in Felipe’s telling—they were never meant to actually have. The baby’s “mission” was to alert its mother to her HIV status before the virus had a chance to decimate her immune system. In this sense, both baby and father’s selfless actions have in common their intention of ensuring Bibiana’s health. Though he characterized the decision as difficult, Felipe never expressed remorse over the decision to terminate the pregnancy.

79 Abortion is illegal in Brazil.
Bibiana, by contrast, intimated regret on every occasion she and I were alone. She was quite explicit direct during her first individual interview: “You know I regret having that abortion, right, Shana? I don’t say anything to Felipe, but I regret it.” She remarked plaintively that, since they would never again have intercourse without a condom, she had lost her only chance to have a child with him. I asked whether she was aware that unprotected sex wouldn’t be necessary and she quickly confirmed, but emphasized that Felipe would still have to consent to a pregnancy: “Felipe is such a chicken-shit. He’s really fearful. He told you, right? That one percent chance [of the baby being HIV-positive], he doesn’t want to risk. I’m braver, I would chance it, you get it? I would, but he wouldn’t. So he’s never going to agree to an insemination.”

At that time she said, almost as though to convince herself, that having a child was something she was going to have to put out of her mind. A month later, however, she first joked, and then spoke more seriously, about inseminating herself without her partner’s knowledge. Having observed Felipe’s practices, she claimed this would be easy. As she reported telling a friend:

You know what I could do, my friend? I let him come in the condom, grab a syringe, go get the condom from the bathroom, shoot it all up inside of me, and say, ‘I’m pregnant!’ And [the friend] says, ‘But, could you bring yourself to do that?’ Of course I could! I already brought myself to have an abortion!! Look, I’m the one that knows. If he doesn’t like it, he can pack up and go!

Her tone became more sober as she mused that Felipe would feel betrayed if she resorted to such tactics. She concluded that she could be patient for a few more years since, in her estimation, a woman could have children without expecting serious problems until the age of 35. Nevertheless, she stated emphatically, she wasn’t discarding the idea entirely. Having another baby was clearly one of her overriding concerns.
Another flashpoint was the couple’s sex life, or, perhaps more accurately, what Felipe’s sexual behavior symbolized for her. Bibiana was never shy, reticent, or inarticulate with me. She was, instead, a rushing torrent of reported experiences, reactions, and reflections. The second time I arranged to visit the couple, she pulled up in their car as I was getting off the bus. She greeted me with a dazzling smile as I climbed in the vehicle, and then dove headlong into the story of her latest fight with Felipe, which had happened earlier that same day. She had taken off with the car and hadn’t returned. She was still agitated, unable to keep the edge out of her voice as she enumerated her complaints. Instead of heading back to the house, she drove to a park.

Soon after we were installed there, however, she returned to discussing details about her physical relationship with her husband that she found frustrating. By way of preamble, she said, “Look, I know he likes me, you know? I do…but—I don’t know how to explain what it is, but there’s something. (pause) He’s afraid, Shana.” She lamented how infrequently they were physically intimate (approximately once or twice a month), as well as Felipe’s behavior when they were. In particular, his near-total avoidance of oral sex seemed to have taken on special symbolic importance. The only other sexual practice she discussed in the same detail or with the same frequency was intercourse (see below), but it was fellatio that she had turned into a “test.” She told of one instance in which she had initiated this behavior and he had resisted:

It was without a condom, ok? [...] So I say to him, “If you don’t want to, you’re not going to stay still and let me, then I guarantee you that if I go out in the street I’ll have ten guys with their cocks out for me to do it.” I said that to him. And I think he felt sort of obligated to let me, you know? But I did that to test him, to see if he would really let me. It’s not that I wanted to do it, you know? I wanted to see what his reaction would be. He let me, sort of annoyed, but he let me.

This was recounted as a small but encouraging victory, a sign that sexual practices that were previously de rigueur for the couple had not been permanently banished from their repertoire.
In other areas, however, Bibiana’s attempts to re-negotiate the couple’s sexual norms had not been successful. The most disconcerting of these involved Felipe’s post-coital practice. He had developed a habit of withdrawing from her as soon as he reached climax, heading directly to the bathroom to clean up, and then returning to bed mostly dressed. She vented:

I already told him that I hate it that he does that, and he keeps doing it. I said, “I detest that you get up from the bed that very second and come back already dressed.” He comes back dressed! All that’s lacking is his shoes!...He puts on his underwear and his shorts and lays down and then to top it all off turns his back to me. ...He wants me to get up pleased-as-punch with him, you know? I get up mad as hell.

This was a clear departure from their past lovemaking, which had been more frequent, more varied, more relaxed—even languorous. She emphasized, however, that it was not his current behavior *per se* that she found galling, but the change: “If he’d always been like this, I wouldn’t think anything of it. But it’s that he wasn’t like this before [the diagnosis], you get it?” Her anger at such actions was discursively linked to (and therefore, we may posit, provoked by) what she saw as Felipe’s irrational fear of contagion.

That not all lovers would harbor similar fears, or react to them in the same way, had already been proven to her. Prior to Felipe moving in with her, but after her diagnosis, she said that she had been intimate with someone else: her ex-husband, the father of her daughter. She told me this off-handedly, and claimed it had “nothing to do with Felipe.” Her ex-husband had behaved sexually, though, as he always had in the past. He had “no fear whatsoever....if [I] tell him to put it in without a condom, he’ll do it. He does oral, he does everything, ok?” In contrast, according to Bibiana, Felipe seemed to think that “even just leaning against me he’s going to catch something…It’s like he’ll put his hand on me and even the liquid that comes out of me, I don’t know, if he has a hangnail, you know, he could get something that way, and so he doesn’t do it. He doesn’t do anything.”
While this state of affairs was not ideal, Bibiana claimed she did not see it as endangering their union, and things did improve slightly over the time I knew her. In any case, she noted that, at her age and having had as many partners as she had, sex was not the most important element of a relationship. Felipe, at least in her eyes, had changed in some ways after her diagnosis, becoming more “closed,” but she felt he was unaware of this: “He hasn’t assimilated it, you know? I think he’s not conscious of having this type of attitude.” She expressed conflicting opinions about the permanence of the changes wrought in their relationship by her diagnosis, sometimes claiming Felipe could not change, sometimes expressing hope that dialog might provide an avenue to deal with the challenges. In spite of this, she characterized their relationship as “marvelous,” saying:

We get along well/are compatible in everything, we go out, we go to the mall, we have fun, we go to restaurants, he provides for me, we go to the supermarket, he makes barbeque, we have *picanha* [a particularly prestigious cut of beef], he gives me presents, and sexually speaking, it’s sort of so-so.

This list of what Bibiana sees as desirable qualities in her relationship with Felipe includes not only traditional roles for him (i.e., “provider,” as well as grill master), but also the notion of “being and feeling subject” and “feelings of protection and trust” that Maksud (2002:11-12) asserts are characteristics of Brazilian conjugal relationships. In this particular instance, the confluence of emotional bonds, normative gender roles, and what Brazilians would call Felipe’s *poder adquisitivo* (essentially, purchasing power) are important; they can be seen as decisive counter-weights to what Bibiana unapologetically portrays as her partner’s underwhelming sexual performance.\(^{80}\) Therefore, perhaps it is not surprising that, overall, she

\(^{80}\) But it should be noted that Felipe’s position, in terms of social class, makes this counter-balancing possible, to a degree quite out of reach of any of the other male participants in this research.
doubted she could find a partner better suited to her than Felipe, and expressed her determination to remain in her marriage.

For his part, Felipe’s only spontaneous mention of the couple’s sex life occurred when he was reporting the kinds of issues he had discussed with Bibiana at the time she was diagnosed. His highly euphemistic comment, “life is going to…going to have restrictions,” was representative of his very limited discourse about the topic. He admitted, in response to a direct question, that the couple’s sexual relationship was not exactly the same as it had been prior to discovering their serodiscordance: “Something always changes, right? Never again…” he trailed off. But sex was not something he characterized as fulfilling or not, frequent enough or not, important or not. Instead, it was what it must be. He claimed that since Bibiana had been diagnosed, the couple had had no sexual contact without a condom. He said that this decision was something that “didn’t require discussion. It was something that happened, and we adapted and accepted it.” I asked if this change in habits had been difficult to make. He denied this:

> At the time it was such a big shock, you know? We didn’t do anything for, I think, two months…because she was afraid that I had…that I’d get [HIV] also. She didn’t want me to come near her. We had to start all over. That's why it was really easy with the condoms. I never had a problem [using them]. Also, it had to be that way, right? It’s like I told her, we’re going to have limitations, ok? The quality of life might diminish but life expectancy can be practically the same, you know?

Bibiana later concurred that immediately after her diagnosis she had not wanted to be intimate with Felipe (and this is frequently reported among those newly-diagnosed with HIV, see, for example, Maksud 2002; Stevens and Galvao 2007). More than that, however, she had thought he should leave her and continue on with his life. He said he had never truly contemplated that possibility. “I would have felt like such a coward. If I liked her before, and now she has this situation that means she’ll need me even more, and I’m going to leave? I would never have [a clear conscience].”
The totality of what exactly would weigh on Felipe’s conscience if he left only became clear to me two months after I met the couple. Bibiana, as usual, was in the middle of an involved story when she mentioned that Felipe had appeared in her life “out of nowhere.” I stopped her to confirm that they had known each other for years; her response, uncharacteristically monosyllabic, was, “Eight.” Because she did not elaborate, I asked how, precisely, she had met him. There followed a pause so long I feared she had not understood my question. Then she said, with strange emphasis, “On the street.” “Really?” I asked, smiling, still not understanding and merely trying to prompt her. She took a breath and told the story from the beginning of how, when she was 21 years old, she became a commercial sex worker.

Bibiana and Felipe’s families of origin could hardly be more different. Whereas Felipe’s father was an autonomous professional who provided a home for his wife and two children in an upper class neighborhood, sent both his son and daughter to university, and provided them with the means to make their own livelihoods, Bibiana’s father had been in an accident when she was ten years old that left him in a vegetative state. She was fifteen when he passed away. Her mother was emotionally distant, which Bibiana attributed to her being an adopted child and suffering from feeling unloved.

Around the time her father passed away, Bibiana was kicked out of her mother’s house; she moved in with her then-boyfriend. She barely finished high school and struggled through a series of low-paying jobs, forming relationships with young men who were in similar straits. She learned, however, that being beautiful and vivacious often was enough of an inducement for men to help her meet her financial obligations, even without consummating a sexual relationship. So when she reached her lowest point, the fourth day of sitting in her dark apartment without any
way to get the electricity turned back on, she answered a Want Ad for female escorts. Soon, she was making “rivers of money.”

Felipe met Bibiana three months after her daughter’s birth, when she went back to working the street. At the time, she was living with—and financially supporting—Janaína’s father, who was a law student. Felipe, who became one Bibiana’s weekly dates, could not understand how her husband allowed her to engage in such work, why he didn’t take better care of her. Over time, Bibiana’s patience with her husband ran out. She had supported him through his law degree, but he appeared to be in no hurry to fight for a job that would support their family and allow her an opportunity to study, or find less dangerous employment. When she finally ended things with her now ex-husband, it was to start a relationship with Felipe, who immediately prevailed upon her to cease sex work. She did, but made it clear to me that, if the relationship were to end, she would have no qualms about taking it up again. She said, “I’m not afraid of these things because I’ve already been there. I’m not going to eat rice and beans and subject myself to that kind of life. No.”

Despite her dauntless assertion that she would return to sex work if necessary, and the financial security her work had afforded her, discussions that touched on her past were not without some ambivalence on her part. She had suffered stigma and social rejection as a result of her profession, and she had contracted HIV from one of her clients. Sex work and HIV were twin shadows on the periphery of Bibiana’s life, secret from all but a few people with whom she currently interacted. The former was the one she guarded most closely, however. When I asked whether she would tell her daughter about her infection, she said she would when Janaína got older, but:

I think more about telling her about sex work than me being sick. Because [...] an illness is an illness, you know? No one asks to get one—or, like me, they sort of do, you take risks and get it, but illness is illness.
Now, one’s past, that whole situation, right? I’m more afraid someone will tell my daughter, ‘Oh, your mom was such and such; she did this and that’ than that they’ll tell her, ‘Look, your mom’s sick.’ You know, because an illness you can get even from your husband; you can be a prim and proper woman and have this.

It was, of course, easier for Bibiana to keep her HIV diagnosis secret because few people were ever aware of her serostatus. In addition, she was in good health overall, and suffered very few side effects from her ARV regimen. As she put it, “I don’t feel anything, Shana. If I said I did, it would be a lie, ok?” A friend of hers remarked that she sometimes forgot Bibiana was infected; she simply did not seem ill. Bibiana commented to me, “But why should she remember? I only remember when I have to use a condom with Felipe and he barely comes before he goes running off to the bathroom! That’s when I remember that I’m sick.” From what she reported seeing and reading in online communities, she said she thinks many HIV-positive people feel the same way she does. Immediately post-diagnosis, it’s challenging to accept, but nowadays, she said, it is possible to have a “normal” life.

This possibility was a frequent, and spontaneously mentioned, theme for Felipe as well. A “normal” life was what he and Bibiana were striving to have; it was what doctors claimed was within reach, given the state of treatment. When asked if he had any advice for couples just discovering their serodiscordance, he claimed he would rather make an “announcement” of sorts: that they could look forward to a “nearly normal life.” The closing thought he offered during his individual interview also invoked the idea that, with “discipline…life can be very close to normal. It’s going to have limitations and responsibilities, right? Everything comes with a price, you know, to pay for such a mess-up/ carelessness. So I think it’s this, that [HIV] is something you can live with nowadays, without serious problems.”

But for all his insistence that life could be “normal,” that living with HIV required only minor accommodations similar to those one would make for diabetes or hypertension, his
narratives are not without contradiction. After asserting that HIV-related challenges facing the couple are essentially reducible to remembering to take medication and dealing with Bibiana’s occasional emotional ups and downs, I asked him if he ever forgot about their serodiscordance. He answered:

[And] have a normal life like that, I don’t...Yeah, yeah, it’s possible to forget. I think she’s the one who doesn’t forget, you know? No, it’s possible for us to have a normal life. We don’t even talk about it much, not after the first moment passed, of finding out and everything. [...] It’s there; it’s something that’s present, not forgotten. It’s no use, you know? We’re very captive/caught by that; we have to go on with life.

Whether it was truly possible for Felipe and Bibiana to have the “normal” life they both so clearly wanted, only time would tell.

Wílian & Pamela

I had identified the first five couples featured in the sketches in rapid succession; it seemed that fears over the difficulty of recruiting for this research were misplaced. Then, as weeks passed without meeting any eligible participants, I began to realize what a streak of luck I had had initially. But one of the nurses reminded me about a patient whom she thought would be “perfect” for the study. She seemed to know him well and be quite fond of him and his wife, who had diligently brought a baby of theirs for treatment at the clinic. Indeed, Wílian and Pamela seemed to have a sort of minor celebrity status with the clinic personnel—all the other nurses, as well as the support staff knew them, many chiming in with laudatory comments. I began to scan the physicians’ appointment lists each day for his name. On the last day of September 2009, he was scheduled for his routine check-up, late in the morning shift with Dr. Verenice. I requested and obtained permission to observe patient consultations with her that day.

I observed appointments with five patients, four of whom expressed some type of emotional distress or presented a clinical condition. In each case, Dr. Verenice appeared
frustrated but unsurprised, and frosty. She did not physically examine any of these patients, remaining seated in her chair behind the desk, though she did give one patient an information sheet she’d prepared concerning common ARV regimens. For a patient potentially experiencing treatment failure, she filled out a document authorizing a viral genotype, scolding him for not taking his medication as prescribed, and sent him on his way. Once we were alone, she turned to me, looking as though she had spent the morning casting pearls before swine, and said, “They don’t understand what can happen. It’s discouraging.” Making a hand gesture that communicates a lack of importance or engagement, she continued, “[Treatment] is not a priority in their lives.”

Shortly thereafter, she called Wílian’s name. A tall man in his late 40s appeared in the doorway. He was lean and gave the impression of possessing the kind of strength that comes from doing physical work. His dark hair was straight and short; his complexion and facial features suggested mixed ethnicity, including some indigenous heritage. He seemed totally at ease, flashing an affable smile as he sat down. Dr. Verenice greeted him warmly, undergoing a metamorphosis so complete that I actually turned to stare at her. She was keen to share with me her praise for Wílian and his wife, calling him “a model patient.”

She reviewed the results of his routine exams, noting that his CD4 count and viral load looked good. Then she inquired about Pamela’s treatment, to which Wílian shook his head. “No, she doesn’t have it,” he said, meaning HIV. “Oh no?” Dr. Verenice looked up quickly, “Didn’t you have a scare last year?” He nodded but said that, thankfully, she had not seroconverted. Dr. Verenice inquired about the rest of his family, his job, and commented again on what an excellent patient he was. There being nothing else to discuss and other patients waiting to be
seen, the appointment was quite short. As he left, I excused myself and followed him out, thanking Dr. Verenice for her time.

In the hallway, I explained the study to Wilian, asking if he could talk to Pamela and decide if they were interested in participating. He was polite and encouraging, especially after I stressed that I did not want him to make a decision without consulting her. We exchanged contact information; he gave me instructions for reaching his house via public transportation. Less than a week later, I was en route to the suburb of Porto Alegre where the couple and their children lived; the area had a reputation as poor and high-crime. It was after six p.m. and the flow of workers returning home from jobs in the capital was crushing. At every stop, more people pushed their way on to the already overcrowded bus; virtually no one exited. Later, Wilian and Pamela nodded their heads when I mentioned this and told me the buses are always like that during rush hour. That was one reason they counted themselves very lucky to have Wilian’s little truck, even though it was 20 years old.

When I finally arrived at the address the couple had given me, I thought I must have been mistaken. The building did not look like a residence at all. It had no windows, just solid concrete walls with a garage door. But I found what I took to be a doorbell and pushed the button, which prompted the three dogs inside to start barking, followed several seconds later by children’s voices. Then a woman’s voice, which I recognized from our telephone conversation as Pamela’s, began calling off dogs and shooing away children. The garage door started to rise.

Pamela smiled and greeted me as though I were a regular visitor to the house rather than a stranger from another country. She was very short, with medium-length, curly brown hair and dancing green eyes. As she ushered me up the steep driveway and into the house, she talked a mile a minute, apologizing for “looking like a housewife,” noting she was preparing dinner, and
that Wilian had not returned from work yet. At the top of the driveway was a large, covered patio area, criss-crossed with clotheslines; we proceeded into the house.

The living room was furnished with two couches, a TV, a long table with wooden benches, and a huge banner with an image of Jesus Christ on the wall. The kitchen was off to the left of the front door as one entered, with no walls to obstruct the view of Pamela’s dinner preparations or the family’s aged appliances. Opposite the front door, a hall went back to bedrooms and a bathroom. The front area and the hall had tile floors, which, the couple was excited to inform me, they had installed recently. Before that the floor was just concrete, like the rest of the house. There was a somewhat rough-hewn and sparse but functional look to the home overall.

These details are of more than passing interest because of the importance of the theme of “building” throughout Wilian’s narratives. Wilian and Pamela had been married for twelve years, and that time—one that Pamela characterized as entailing “a lot of struggle”—saw not only the reconstruction of house in which the family lived, but the putting together, piece by piece, of the family itself. Both members of the couple had been married once before meeting each other, and both had children from those previous unions. Pamela had one daughter, who had been nine years old when her mother had married Wilian. She had lived with the couple for eleven years, until her own recent marriage. Wilian had three daughters, aged 25, 21, and 18. The oldest still lived with the couple; she was employed and taking college courses on a scholarship. The middle daughter had married and moved away. The youngest, Laura, lived at home and was already “retired” due to disability. The couple told me she was autistic. She had no apparent physical limitations, but I never heard her speak or saw her meaningfully engage with anyone. She frequently moaned and yelled incoherently. On all three of my visits to the
house, she seemed restless, sometimes sitting on the couch next to me, sometimes standing in
front of the television, sometimes wandering off down the hall. She needed constant
supervision. Wílian told me they had built those tall concrete walls around the house to keep
Laura safe.

Wílian’s marriage to his ex-wife had ended around the time of Laura’s birth. He had
grown up in a small border town, close to Uruguay, in a large, very poor family. He said this led
him, as a young man, to put a high priority on establishing himself professionally. To that end,
after he and his ex-wife had their first daughter, they moved to Porto Alegre, the state capital.
He claims he told his ex-wife when she was pregnant with their second child, “I have nothing. I
want to learn a profession, have a house, and to achieve that, you have to stop having one child
after another; we’re going to stop right here.” He was working as a mechanic, learning on the
job. He saw limiting the size of his family as necessary to ensure the standard of living he
desired. As Pamela told me later:

“He made a good life. Wílian had a workshop, he came from
nothing. He bought an apartment, furnished the apartment, they
had those carpets that your foot sinks into, his oldest daughter went
to a private school. They had a babysitter, his wife had everything
a woman could want. [...] but still she started to cheat on him.”

The couple separated, but, according to Wílian, his ex-wife didn’t stop having children.
She had two boys, each of whom was the product of what Wílian insinuated to be passing, if not
utterly casual, affairs. About his own behavior, he said, “You know how single guys are, going
out with one [woman], going out with another.” He had many sexual partners during this period,
but no stable relationships. He visited his daughters frequently, and the boys began to call him
“Dad,” too.
Pamela’s experience with marriage was, if anything, even more painful. At sixteen, working at a supermarket, she met the man who would become her husband. They began a relationship, and when she became pregnant, they moved in together. When she described getting married, however, it seemed to be almost as much about what she was choosing to leave, as what she was choosing for her future: “I thought I was in love with him because my life was always very hard; my step-father used to beat me when I was a child...the last time he beat me I was sixteen and he almost broke my face.” Pamela was around twenty years old when she realized she did not love her husband. She decided nonetheless to remain married “because it [was] better than being in my mom’s house.”

Pamela began going to school at night, attempting to finish the Brazilian equivalent of eighth grade. During this period, her husband also acquired a new occupation for his evening hours: an affair with her childhood best friend. Eventually, he stopped coming home altogether, except to shower and change clothes in the morning before heading to work. This was a low point of Pamela’s life. “I have to tell you; I wanted to die. I went to the medicine cabinet while my daughter was sleeping and started trying to find something that would kill me without causing a lot of pain. Seriously. Because I just couldn’t take it anymore, it was too much for me.” The couple was married for ten years.

Pamela was not working at that time, so when her husband stopped supporting her and their daughter, she had few options. The most logical, to return to her mother’s house, was also intensely dispiriting. Aside from the bad memories of the physical abuse she’d suffered at the hands of her step-father, her brother-in-law frequently harassed her. He and her sister lived in very close proximity to, and frequently visited, the girls’ mother. Even while Pamela had been married, her brother-in-law had habitually done things like lifting her skirt, or pushing her
against the wall and kissing her. Although she dreaded his advances, she did move back in. To finally put a stop to his behavior, she resorted to threatening him with a knife. She noted that she had begun to fear men at that point, and closed herself off from any kind of relationship.

This period was not all tragedy and drama, however. Eventually, Pamela’s sister separated from her philandering husband and also moved back home. The two of them would drop their children off with their respective fathers on the weekend and go out dancing. Pamela’s face lights up and she laughs as she tells me:

We would come home in the morning, with our shoes in our hand, tired out from dancing all night, makeup and hair a mess. We’d go to the bakery to get some bread, have some coffee and take a shower to get all the sweat off, you know? We’d sleep, eat something, and go out partying again...there we went, the two of us (laughs). That was when I had my adolescence. During that time I really lived life, you know?

She also got a job as a cleaning woman, although she says most of her money went to pay household expenses for her mother, who remained very demanding in terms of the domestic work she expected Pamela to do. Pamela’s relationship with her natal family had historically been complicated and taxing; she says she was treated terribly because Pamela’s biological father had refused to marry her mother, who was his first cousin. Pamela felt she had always been the family scapegoat, and likened herself to Cinderella, seen as a virtual servant by her siblings and her mother.

One particular day, before work, she sat reflecting on her disappointing life. She was contemplating moving to a new state, taking her daughter and starting over where no one knew her. Though she wanted nothing more than to be left alone with her thoughts, a co-worker persisted in talking to her. When this woman commented on a man she saw approaching,
Pamela looked up to see. Her co-worker continued talking, but Pamela no longer had any idea what was being said. She recounted the story almost breathlessly, still enraptured:

Wilian, scruffy, unshaven, with a belly and dirty clothes, because he had no woman to take care of him, you know? Shana, I looked at him and it was like, “Bang!” He looked at me, I looked at him, and the two of us just stared at each other…it’s like we were hypnotized, you know? And [I thought,] “Now what do I do?” I ran my hands over my hair, thinking, “This is the man of my life! Just look—oh, what a man!”

Wilian was instantly taken with Pamela, too. He remembered stopping that day at the same little place he usually did, to get a cup of coffee. Across the street, he saw “this tiny little thing that weighed 40 kilos, with green eyes.” He brought his coffee outside and, smitten, continued to watch her. She came across the street and into the establishment to buy something; he pointedly said, “Good morning,” but she said nothing. Pamela, having invented this errand on the spot to try to hold his attention, said she was so tongue-tied inside the shop that she could barely ask for what she wanted to purchase. When she came out, he caught her hand and said, “Now, you’re not going to leave it at a smile, are you?” and invited her to lunch. Both of them emphasized her surprise at this forward gesture, and how she tried to pull her hand away. Nevertheless, she managed to dominate her emotions and interrogated him about his marital status before giving him her phone number. A week later, Wilian was meeting Pamela’s family and making their relationship official.

The Wilian who so captivated Pamela that day, however, was no longer a “love-'em-and-leave-'em” bachelor. As he explained, “Now, I’m going to tell you something: No one wants to be infected with [HIV…] but it was just the thing to stop me in my tracks. Finished, done, caput. From that moment on, I couldn’t even come close to a woman.” This had happened two years before he met Pamela. He said that during the early- to mid-nineties, media messages urging
people to be tested for HIV were ubiquitous in Porto Alegre. Although he did not understand much about it, he knew enough to draw a connection between the multiple unprotected sexual contacts he was having and the possibility of infection. So he got tested for HIV periodically.

On the day his results came back positive, “My world came crashing down….It’s a situation that makes people feel very alone, it’s something you can’t talk about with anyone, you know….The person feels banished from the world.” He told me that, though there is still a significant amount of prejudice and discrimination about HIV, back then it was much worse. Another difference was that in the mid-nineties, everyone who was diagnosed with HIV was immediately prescribed ARVs, regardless of CD4 count. So Wílian began a pharmaceutical regimen, even though he had never had an opportunistic infection. He thanked God that he had been referred to the clinic and praised the treatment he received there. He emphasized the multidisciplinary nature of care, singling out for special approbation a psychologist, his doctor, and the nurse who had mentioned him to me. “They knew how to talk to me... and they started to work on [literally, “polish”] my head and I saw that things weren’t so hopeless.”

Another issue, however, was crying out for Wílian’s attention. His children were not well-cared for; they had lice, ran around unsupervised, even naked. The house had fallen into disrepair and the mother did not, or could not, do anything about it. “It didn’t have a cement floor, it didn’t have a front door—everything was open. It didn’t have the outside wall or the covered patio area, it didn’t have anything, it didn’t have windows; the windows were all made of old wood and falling to pieces.” It tore at Wílian to leave his children in such a situation. But he told me that, “In a house without a mother, it’s no use to have money, because you can bring it in by the shovel, but it leaves by the truck-load.” He “cried out to God” to find the right woman to help him with his “principal objective of being able to rescue [his] family.”
Such are the makings of this real-life love story: an attractive woman, pushing 30, with a child, and consistently mistreated by the men in her life, is sorely tempted to risk everything for a fresh start. A handsome, hard-working, former-Cassanova has his life shaken up by a dreaded diagnosis and dreams of making a decent home for his children. Twelve years later, the couple’s delight in each other is still palpable. They are by far the most affectionate couple in this sample, constantly calling each other pet names and routinely touching. They also report the most active sex life, averaging three times per week.

Wilian, at the time he met Pamela, had not disclosed his HIV diagnosis to anyone. That he had not told his family was perhaps unsurprising, since he, much like Pamela, felt like the black sheep of his kin group. Wilian has ten siblings and he noted that they all “gamble, drink, and smoke.” He noted that because he and Pamela have none of these “vices,” “we aren’t very well accepted” at family gatherings. Pamela agrees: they all call Wilian a “stick-in-the-mud.” But it was not merely from his family that Wilian kept his serostatus. His co-workers, with whom he had, in the past, gone out carousing, were also unaware. As he told me, “The problem was just mine, no one at work knew…I didn’t talk to anyone. I saw people dying around me, co-workers of mine from the firm close to where I worked with this problem. I also saw clients from where I worked die from this problem. […] I kept quiet.

With the advent of their relationship, however, “keeping quiet” no longer felt like an option to Wilian, at least with Pamela. “I thought I had to tell her because it wouldn’t be right before God, before God it wouldn’t be honest for me not to tell her about something like this, you know?” I asked him if, given how much he liked her, he was afraid of what her reaction might be to this disclosure. He answered, looking—all these years later—still quietly resigned:

I liked her a lot but I think the sense of responsibility was greater than my fear. I thought, “It could happen that I tell her and she simply doesn’t want to continue with the relationship,” right? […] But how can
you live with this kind of [secret]? There’s no way, you know. I said [to myself], “I am going to tell her. If we’re supposed to be together, we will be.”

The couple’s accounts of the conversation that ensued were quite different, however. Wilian emphasized the information he offered Pamela about HIV, using technical—almost clinical—vocabulary to explain why she had nothing to fear:

I told her, I have this kind of thing…I said that I am a person who doesn’t pose a risk for anyone. Because I, I—how do you call it? The viral load… the viral load is low. If we are careful and do everything right, we don’t run any risk. I even took her with me to the doctor to do her HIV test.

Pamela, on the other hand, emphasized the emotional aspects of the interaction. I asked her in her individual interview if she remembered what Wilian had said when he initially disclosed his serostatus. She said the couple had gone to a motel, and they were sitting on the bed when he took her hand and said, “I have something to tell you.” Pamela continued:

He looked me right in the eyes and I said, “Go on.” My stomach sank, you know? My hands started to sweat, my feet and arms weak, I was very nervous. “Go on, say it! What do you have to tell me?” [He said,] “I’m in love with you.” “Is that it?” [she said, relieved]. He [said]: “No...” and then he told me. You know, Shana, I’d never heard of that disease….Not at all. I hadn’t heard about it. I knew there was such a disease that my mom talked about, but I didn’t have—you know? I always protected myself, used a condom with the boyfriends I had. From fear, you know? So I looked at him and I said, “It doesn’t matter; I love you all the same.”

Pamela had obviously not been affected by the messages regarding HIV testing that Wilian claimed were everywhere at the time. Perhaps because she had no framework with which to make sense of the information he gave her, none of his talk about “risk” appears in her

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81 A “motel” in Brazil is a place specifically for having sex. Rooms are rented by blocks of time, with the minimum duration varying by type of client to whom the motel caters. Some, located close to areas well-known for commercial sex work, charge per hour, while other, more expensive places have a three-hour minimum, for example.
narrative, which focuses instead on his seriousness, her own anxiety, and their mutual elation as the situation resolved.

Wilian and Pamela moved in together and for two years they lived in a tiny little house; Wilian’s children still lived with their mother. Pamela said about this time, “It was hell. Every day the telephone would ring, “Dad! Mom left!” Dad this, and Dad that. I couldn’t take the weekends […] when the kids would visit them; the house was so small. And they were such brats. They had no limits […] because] their mom never taught them.” This situation was difficult for Pamela because she could see that these children had never been nurtured or cared for the way her own daughter had, but that experience had made them, in her eyes, selfish and wild.

According to Pamela, things went on this way until the day Wilian’s ex-wife “slapped the oldest girl across the face. That was it, ‘that threw flour in the fan,’ as they say.” Pamela supported Wilian in his resolve to try to win custody of the children—and not merely his own daughters. Although it nearly doubled the size of his family, he decided to appeal for parental rights to the boys as well. He explained his decision to me: “Even though they weren’t mine, I decided to take responsibility for them […] I was afraid of my conscience; I couldn’t turn my back on them.” Despite a bureaucratic run-around, when it finally came time for the hearing, Wilian’s ex-wife voluntarily gave up her rights.

Once the couple won custody of the children, they needed a bigger house. They traded homes with Wilian’s ex-wife, which meant the adults moved but the kids weren’t uprooted. Pamela had showed me photographs, which supported her disgusted description of the place as a “mausoleum, from a horror film […] It was dirty, dirty, dirty,” and in severe disrepair. At the time, Pamela’s mother was dying of cancer, and Wilian had done everything in his power to help
her. Nonetheless, she warned her daughter against staying with him, saying, “I know you’re grateful to him for everything he’s done for us, but think twice. To go that house and raise those children that are not yours, that have been brought up in a different way—hardly ‘brought up’ at all, that is going to be very difficult.”

These same thoughts had occurred to Pamela. She told me that sometimes she sometimes looked at Wilian, thinking:

“It’s to this shithole that you want to bring me? This damn dirty house?”

It didn’t have a bathroom, the rooms had no doors, you know? All that stuff: the kids had no clothes, they didn’t have beds, I almost lost my mind. He said, “No, we’ll fix it little by little,” and so we started our struggle. He and the kids, we all did everything, the patio, the roof for the patio, the driveway. The first thing we did was to put up the wall and the gate because Laura kept running off. And then we started doing the concrete.

Life was hard with six children on a mechanic’s income. In order to earn enough to make ends meet, Wilian agreed with his employer to work “informally,” that is, without carteira assinada (literally, “signed card”). It is working with carteira assinada that provides access to rights like vacation time, unemployment insurance, or disability or retirement benefits that are calculated based on the salary a worker has historically received. The cost of these benefits, however, is normally borne by both employer and employee, in the form of taxes. The “informal” arrangement Wilian worked out with the auto shop owner entitled the mechanic to 50% of whatever work he brought in. It also allowed his employer to avoid paying any taxes on this work to the Brazilian government. At the time, both the world economy and Brazil’s were booming; Wilian had steady work, and his take-home pay increased. It seemed beside the point that he did not receive a fixed salary or benefits.

This is the period both Pamela and Wilian referred to fondly as “the fat cow years.” Still, the “luxuries” they allowed themselves amounted to not scrimping on the portions of the three or
four different kinds of food they ate at meal time, having soda pop to drink, and taking the kids
to do fun things occasionally. The rest of the money went into the house. Wílian stressed that
with Pamela’s management of the household budget, and their lack of spending on alcohol or
cigarettes, his income went far. He asked me rhetorically, during one of the interviews, if I knew
how much a case of beer cost then. I obliged him by asking how much. He told me, “A sack of
concrete.” His father had been a stone mason and Wílian himself had been forced to work as a
child to help support the family, so he knew his way around a construction site. Everything, he
said, from the plumbing to the electric wiring, they had done themselves, as they could afford it.

As the house was re-done from the inside-out, the people living there were attempting to
settle in to their new relationships. When I asked the couple, during their joint interview, if it
had been difficult to bring their two families together, Wílian said no, offering the example of
Pamela’s daughter, who still called him “Dad.” He acknowledged problems with “normal kid
stuff,” like chores, but claimed he had ways of pulling the recalcitrant in line. Nearly two
months later, however, when I interviewed Pamela alone, she had a different perspective:

Wílian and I separated two or three times [...] not because of us; our fights were always about the girls. They’re stuck-up, you see? They don’t see me as a good person, [they don’t say] “Oh, how great that my dad’s with a nice woman, that he brought someone to make food, to take care of our brothers. Our house was never so clean, we never had a mom like that.” They don’t see me like that, they see me as an intruder [...] Even today.

Pamela was clearly anguished as she confided this. She looked tired just recounting this
anecdote. Though I knew the situation was surely much more complicated than the brief account
she shared, my heart went out to her. As a researcher, though, I was pleased. Without this crack
in the fairy-tale, I might have been less inclined to believe the rest of their story.

The stormy bits of their relationship, however, could not compare to the episode of The
Wall. During their joint interview, the couple noted how the “fat cow years” had ended abruptly
one winter, when one of the exterior walls of the house caved in. The couple embellish and affirm each other’s assertions; neither one entirely ceases talking during this whole exchange.

There is an urgency to their utterances, but, especially on Wílian’s part, it is emotionally flat. They gestured to the affected areas of the house as they explained:

Wílian: It rained and we didn’t have the money for the cement that would strengthen the wall from outside. So the water got in and put pressure on the wall, and it caved in.
Pamela: And we lost the whole kitchen—
Wílian: With the water that came in behind the wall, you see? And when the wall fell it broke everything, it broke the stove, the [other] wall, our things—
Pamela: This wall here—this wall we lost, the whole length of the house, plus the kitchen that I had right here. I had an old refrigerator, but at least I had one, you know? An old, used microwave—
Wílian: We had to start from scratch—
Pamela: We lost everything, the stove, the refrigerator, everything we had in the kitchen—
Wílian: But I knew it could happen! But there wasn’t enough money; there was just too much that needed to be done.
Pamela: And so we were left without a wall here for half a year—
Wílian: It was a black tarp.
Pamela: Yeah, we put up a black tarp, Shana.

At that particular point in time, Wílian’s earnings had dropped off. Winter is the wettest part of the year in Porto Alegre, and low temperatures can sink close to freezing, so rebuilding was a high priority. But at a cost of R$ 5-7,000 (which was approximately twice the highest weekly sum Wílian ever earned during the best times), it took time. Pamela remembered how she let the children sleep until 11am because she had nothing to give them for breakfast; she shook her head as she stated it had been difficult. Wílian, however, said it could have been much worse; one of the children had been caught in the collapse but had escaped relatively unharmed. He said he had led Pamela to the room where the kids were sleeping, and told her, “Look, they’re all here. What happened was material, but we’re going to get back up again.”

I sat listening to this man, who seemed to have struggled so tirelessly for his family, and saw that the characteristic, mischievous gleam in his eye was gone. So I asked him, in
amazement at his fortitude, and perhaps not gently enough, if it had not been difficult, at that moment, to take the long view. His eyes immediately filled with tears, and Pamela moved to soothe him. His throat constricted around his answer as he nodded, “It was horrible—oh! I don’t even like to remember it...” With that, he jumped up from the table and strode over to the now-rebuilt wall, making sweeping gestures with his arms to clarify exactly how they had reinforced the structure to avoid a recurrence.

The house was more structurally sound after those renovations, but the family within was not yet complete. Pamela acknowledged that, when she and Wílian got married, she would have liked to have more children but, HIV aside, he had had a vasectomy before they met. And after a few years of living with all of the children, they were both too overloaded to want to add anything else to the list of demands competing for their attention. Like many rational decisions, this was utterly practical but did not stand the test of time.

“One fine day,” as Pamela frequently began particularly engaging stories, Wílian’s ex-wife dropped by. It was shortly after the kitchen wall had caved in. She told Pamela that she was five or six months pregnant, but she was thinking about taking an abortifacient. She asked whether the couple wanted the baby. Pamela said she felt “a rage at her, a hatred, because I wasn’t talking with some teenaged girl, caught unprepared. I was talking to this old donkey in her 40s.” After talking it over, Wílian and Pamela decided they would offer his ex-wife a deal: they would think about adopting the baby if she would get a tubal ligation.

Their hesitation was not entirely born of doubts about their ability to be good parents in their current circumstances. Wílian’s ex-wife had shared one more bit of pertinent information during her visit: she was HIV-positive. Pamela knew that, at least for her sons, this woman had
not gone to a single pre-natal visit. If that pattern repeated itself, the baby clearly stood a chance of being born infected.

As it turned out, such concerns could not blunt Pamela’s desire to adopt the child once she laid hands on him. She exclaimed to me over how pudgy, and dark-haired, strong, and perfect he had been. They had no money to purchase a crib, but they took the baby, Max, home nonetheless; he slept for months in a supermarket shopping cart that had been padded with blankets. Pamela brought Max to the HIV clinic’s pediatrician, who was responsible for his routine care as well as ARV treatment, for a year and a half. Happily, repeated tests revealed he had not contracted the virus.

Because Wilian and Pamela were recruited later, and lived so much further away than other couples in this sample, I had fewer opportunities for informal interaction with them. In addition, the constant presence of the boys, who didn’t know about their father’s serostatus, limited what could be said when I was with them. We did, however, talk about HIV, and I was acutely aware of the way Wilian had been introduced to me at the clinic, and the impact that might have on what he felt at liberty to divulge. None of my other participants had the pressure of being called “a model patient” in front of me by the clinic staff; I felt it was my responsibility to make it clear that I was interested in his perspective and experience, no matter how it squared—or didn’t—with what he told his doctor.

Wilian, as previously mentioned, had been taking ARVs since he was diagnosed, in the mid-1990s. In that time, he had only one troca. It had been prompted by Dr. Verenice’s assessment that Wilian’s original pharmaceutical regimen might have been causing cramping in his legs. Wilian himself had come to the conclusion that these cramps had, in fact, been “hereditary,” since his father had them, and his daughters did, too. Nonetheless, he was satisfied
with his current regimen, which required two different pills: one that was taken every twelve hours, and another that was taken once a day.

I asked him if he had any difficulty following his treatment, but he claimed it was unproblematic, simply “part of his life.” As he elaborated, it became clear that Pamela was very involved: “She always goes to bed with a glass of water (all laugh) and she gives me two pills. I take two pills at night, one in the morning….in the morning, I wake up, I go to the bathroom, brush my teeth and then she’s there with the pills in her hand. It’s become routine.”

Whether or not Wílian would remember to take his medication by himself, he didn’t have to. Further, he didn’t find Pamela’s actions irritating, in clear contrast to the situation that pertained between Bibiana and Felipe. In part, this may be because Pamela’s actions in this domain of her relationship with Wílian fit in well with a dynamic that characterizes their interactions more generally. This dynamic came up spontaneously the very first time I visited the couple at home, and Pamela’s role in helping Wílian take his medicine was mentioned as a specific example. He told me he’s “lucky” because Pamela is “the last mélia.” I had never heard that word before, so he had to explain that a mélia is like a geisha, “a woman who does everything” for her man. He listed a series of things Pamela does for him (including bringing his pills to him), constructing this as an active form of caring or nurturance, something he valued very positively. His phrasing, “the last mélia,” also suggests that this type of behavior has a historical precedent, but is dying out. Indeed, Pamela told me her sisters scold her for doing all those things for Wílian, implying that such behavior represents a retrograde understanding of marital relations.

Normative judgments aside, this emphasis on caretaking is of a piece with traditional Brazilian notions of femininity, and this underlying ideal echoes throughout the interactions I
had with the couple. At one point during their joint interview, Wilian notes that he became more playful after the first years of their marriage. Pamela responds by discursively constructing him as another child to be taken care of:

(To Wilian) You are like a kid! (Turning to address Shana) It’s like I have eight children, counting him, you know, because Max doesn’t sleep at night without having his milk, and [Wilian] says, “I want my milk, too!” And then they get into it: “No, [Max’s] milk is first.” “No, mine first!” And with their play-fighting, I have to take milk to both of them!

She is clearly amused by this dynamic as she tells this story; the exasperation that infuses her narration of their back-and-forth is merely for show. What is serious and unquestioned, however, is her responsibility to bring milk to her “boys.” Both partners appear to agree about this. Wilian’s first response, when I asked him about the qualities he likes in Pamela, was:

“She’s an excellent mother, a ‘stove-and-oven mother’ […] she knows how to pamper.” As he continued, however, the frame of reference for his praise switched, from “mother” to “woman:”

“She’s capricious/particular, vain, clean, and sweet-smelling”—everything his ex-wife wasn’t.

A little explanation is necessary in order for English-speakers to understand the implications of these phrases for Brazilians. The first two adjectives Wilian used to describe Pamela may seem like precious little praise. Such is not the case. In previous fieldwork on cosmetic surgery in Brazil (Hughes 2005), I found that my research participants—whether current or former patients, medical personnel, or the general public—consistently used the word “vaidade” in a positive way when referring to an individual’s (and particularly a woman’s) concern with personal appearance. For a woman to have vaidade is not only acceptable, but applauded, because it is vaidade that motivates her to “take care of herself,” that is, to do the hard beauty work that is seen as desirable in Brazil. Vaidade, however, is usually translated as “vanity,” which has a negative, and hence, inappropriate, connotation in English.
A similar problem arises here. The second adjective Wilian offers about Pamela is “vaidosa,” which translates as “vain;” but, again, this gives the wrong impression. Likewise, “capricious,” in English, calls to mind arbitrariness, fickleness, and being temperamental—none of which are desirable qualities, except perhaps among female celebrities that populate tabloid headlines. *Caprichosa* in Brazilian Portuguese, however, means being “choosy,” upholding high standards. This attitude is often seen as resulting from concern with the quality of a resulting product. Particularly in this instance, as it is followed by other adjectives dealing with personal appearance, one should interpret *caprichosa* as meaning Pamela is exacting in her hygiene and beauty self-care—and Wilian is the pleased beneficiary.

Pamela herself abides by traditional dictates regarding femininity in explaining her life to me. She consistently foregrounds her role as wife and mother; conversations that deviated from this pattern occurred during her individual interview, which was conducted without Wilian’s presence, and after developing substantial rapport with me. She made use of the trope of female sexual inexperience in describing her confusion and shock at developing a gynecological condition (which turned out to be an STI she had contracted from her then-husband) toward the end of her first marriage. Her status as the “wronged” party is guaranteed by her innocence: “Shana, because I was a girl who was raised in the house. So I never had malice/mischief in my head; my daughter’s father was my first man. I lost my virginity to him.” In sharing this information, Pamela emphasizes being brought up “in the house,” the unspoken subtext being that she was not brought up “on the street.” This takes for granted cultural knowledge of the *rua/casa* distinction in Brazilian society (as previously described in Chapter 3), and its implications for “proper” gendered behavior.
When she did spontaneously, albeit largely implicitly, discuss a sexual relationship, it served to ensconce physical intimacy even more firmly within a context of emotional connection, in accordance with traditional understandings of appropriate female sexuality. In this excerpt, she elaborates on her resistance—despite her family’s encouragement—to continuing a relationship she had with a very handsome man, prior to meeting Wílian:

For me, there has to be something more, and going to bed with a guy for whom you feel nothing is horrible. Horrible, horrible. Even if you’re going out with him, I don’t know, it has no charm, you know? I looked at this guy and thought, “I don’t know, I wasn’t brought up for this, I’m not like this.” I wanted someone who I was really into, you know?

Unlike Iara, Milene, and Bibiana, Pamela never even suggested that sex could be fulfilling as a physical act in and of itself. This is not to say she could not have felt that way; merely that it might well have required a much deeper rapport for her to admit it.

For both partners, too, recourse to traditional notions of masculinity was common. As already noted, Wílian construed having multiple, casual sex partners during the years after his divorce as behavior I should understand as being typical, or normal for a “single man.” If anything, Pamela spoke this way even more emphatically and frequently than Wílian did, claiming as shared knowledge between the two of us that men are untrustworthy when driven by carnal desires (meaning, more often than not). But other aspects of masculinity also came into play, particularly strength and self-sufficiency. For example, Wílian contrasted his mother’s wish, when she found out about her son’s serostatus, to know who was “at fault,” with his own opinion. He told her, “It was me, mom. I’m a man, I’m responsible, I should have taken precautions. It’s not ‘the others.’ I’m the one to blame for my mistakes.”

This self-reliance, as noted in the literature, can extend to a rejection of the necessity of medical attention. As Wílian wryly noted at one point, “Us men, we don’t really like doctors.” On other occasions, he told stories on himself that personalized this supposedly pan-masculine
trait. Specifically with reference to his reaction to being diagnosed with HIV, he said, “I was always the kind of guy [that would say] ‘I’m made of steel. I don’t get sick.’ …So in the beginning, I was a wild animal; I didn’t take my medication…the mélia straightened me out.” It is worth noting here that Wilian’s “wild” masculine impulses are “domesticated” by Pamela’s caretaking. This type of interaction allows both partners to fulfill their prescribed gender roles.

Given the degree to which Wilian can be seen to embrace traditional aspects of Brazilian masculinity, one might expect him to view condom use negatively. When I introduced this topic in the second interview, they had already made reference to their adoption of safer sex.

Shana: And so you were able, from the beginning, to use condoms?
Wilian: Hm-hmm. Every time I pick my meds, I bring them home too, you know?
Shana: But...Isn’t that a drag?
Wilian: In the beginning, but then you get used to it.
Shana: Uh-huh? … Could it be? (all laugh) …I really doubt it.
Wilian: You get used to it, you get used to it. (I look at Wilian skeptically; he returns my look like, “What? There’s no mystery”)
Shana: Huh (as though perplexed)… But it’s not—It’s not like, (sighs heavily, and then, in a fed-up tone of voice) Oh, c’mon! Every once in a while let’s not use it?
Wilian: No. Can’t do it. I love her a lot. (Pamela giggles)
Shana: But, you know, other couples say the same thing [about loving each other]—I don’t think it’s a lack of love that makes them not use condoms. But you see it that way?
Wilian: The way...the way I see it is.... (quietly, simply) I couldn’t live without her. (gradually resumes a less grave manner) I don’t know what her defenses are like, if they’re like mine. Maybe my defenses are much better than hers.... She’s already a child of cousins; that’s why she’s that size [i.e., so small]. Now, it might be that her genetics are stronger than mine. But, you don’t play around with things you don’t know about, you see?…That would be screwing up; we’d be making a mistake we shouldn’t make.

By all indications, then, adherence to safer sex is unproblematic for the couple. Wilian emphasized that, just as he and Pamela are not like other couples in their respective families, he believes he is probably unlike many patients at the clinic. His HIV diagnosis, he says, merely catalyzed a process that “completed what had to be done to not worsen my kind of problem.
Now, other people aren’t like that; they drink, they smoke…. They’re married but still switch partners.” He had not engaged in those behaviors even prior to becoming aware of his serostatus. The “missing piece of the puzzle,” so to speak, for him was using condoms.

Like the model patient Dr. Verenice claims him to be, Wílian’s response to my question constructs the risk of infecting Pamela with HIV as categorically unacceptable, his love for her making it impossible to even contemplate. He then further justified their practice by reference to another discourse often-heard in the clinic: the pseudo-immunological one of the body’s “defenses.” The fact that the body’s response to HIV, as well as to ARVs, varies from person to person frequently figured in conversations I heard and participated in at the clinic—among health professionals and patients alike. Here, this uncertainty regarding the course of infection is mobilized to accentuate the gravity of potential transmission, making it fundamental to avoid.

Compared to the stories of house construction, alienation from extended families, and the random but expectable drama that comes from having seven children, Wílian’s monthly stop by the clinic to pick-up condoms and his medication, and his four-times-yearly routine check-up with Dr. Verenice seemed a footnote in the couple’s life. Those demands were certainly not the ones either partner mentioned when I asked them what had been their “greatest worry over the past week.” That answer never varied. It was always: “Bills.” Wílian’s agreement with the owner of the shop where he worked had served its purpose when all seven children were young, and household expenses were highest. But current monthly expenditures are less onerous. In addition, he claimed the “world economic crisis” was impacting Brazil and he had seen a reduction in work available to do, even though he still worked six days a week. He lamented that it had been nearly two decades since he had a vacation. I asked him if it would be preferable to work with carteira assinada now, and he agreed; he would benefit greatly from the security of
formal employment. However, having exited that labor market, returning is difficult. Although he claims to be tremendously skilled, able to rebuild any kind of engine, he says employers want younger workers.

Wílian said that they lived month to month, getting by because they have access to small amounts of credit—credit he applauds then-President Lula for forcing companies to extend to poor people like him. He also reiterated his gratitude for his little pickup truck, as he explained the couple’s other main strategy: buying food from large distribution centers instead of at retail prices. Showing me a pantry area that was stocked with sacks upon sacks of rice, sugar, pasta, and gallons of cooking oil, he said the only way he can afford to keep his family fed is if he buys in bulk.

The last time I was at the couple’s house, Pamela had concluded a particularly heart-wrenching story about Max, and I told her that HIV seemed to me to be the least of their problems. “That’s right, that’s right,” she agreed. “Am I wrong about that?” I asked her. “No!” she cried, “That’s how it is.” She talked about how taking care of the kids tired her, but speculated she’d have to find some way to earn at least a small amount of money to ease the financial constraints the family faced. As for Wílian, he also acknowledged serious economic challenges, but was characteristically optimistic. Remembering what it was like to be one of eleven children in a poor family, he told me:

I was the kind of kid who went to rich people’s houses, knocking on doors to ask for old bread to eat. So I learned—life taught me one thing: It’s possible to build anything, as long as you have a good heart and goodwill, you can do it. All this (he looks around the house he and his family have constructed) is a dream I had in my head that I knew one day would come to pass. And, thank God, here it is.
Conclusion

The objective of this chapter was not only to acquaint the reader with the history, personalities and current situations of the HIV-serodiscordant couples that participated in this research, but also to elucidate important forces that impact all the couples in some way. The challenge was to accomplish this while taking seriously the contention that HIV, serodiscordance, and risk are multiple, contingent, and complex phenomena, and that imposing a predetermined framework on these experiences may preclude our ability to truly understand their expression as this varies across contexts. In order to explain my approach to this endeavor, a short discussion of the function of discourse in social life was provided, utilizing James Paul Gee’s (2005) conceptual understanding and terminology. Next, in a focused consideration of four dynamics (social class; gender, sexuality, and reproduction; serostatus; and stigma) central to the social production of risk, I highlighted particular couple sketches as exemplifying certain trends.

After thus preparing the reader, each of the six couples is featured in a separate sketch, written to convey the overall impression I gained of their life together after spending time with them in the clinic, at home, and other varied environments. Although the sketches do not follow a standard format, I hope this will, rather than confuse the reader, make each couple’s story more memorable and unique—as they are in real life. The sketches, taken together, make evident the variability of HIV’s role in couple’s lives, as well as the strategies they employ to manage the possibility of transmission, and the meaning they ascribe to serodiscordance. For instance, in some sketches (that of Wilian and Pamela, or Xavier and Juliana) HIV can appear almost entirely backgrounded, with other, more pressing issues (making ends meet, other health problems, raising children, etc.) taking precedence. Or it can figure more or less prominently in couples’
daily consciousness, whether as a source of anxiety (Rita), irritation (Bibiana), or support (Iara, Renato). Further, these dynamics do not correlate neatly with attempts to prevent intra-couple HIV transmission. Consistent condom use is employed within couples who barely mention their differing serostatuses, as well as those for whom HIV is a marked concern. A similar statement can be made for couples who use condoms sometimes or not at all. In short, if there are patterns to be discovered that explain these diverse behaviors and conceptions, a deeper level of analysis is needed to uncover them.
CHAPTER 6: DISCOURSE ANALYSIS

Introduction

The foregoing couple sketches demonstrate, much as Persson (2011:13) has argued, that the apparent singularity, or uniformity of experience, of a phenomenon like serodiscordance can evaporate when we study it through the lens of “what is ‘done in practice’.” As a partial answer to the primary research question animating this dissertation, the sketches provide a holistic understanding of the role HIV plays in the couples’ everyday lives, showing that no simple characterization—either across or within couples—will suffice. This chapter picks up one of the themes frequently expressed by these couples, that of HIV’s relative unimportance, and uses it as an entrée to a focused examination of the construction and negotiation of risk of HIV transmission.

In the first section, I report findings that have antecedents in the literature on HIV, serodiscordance, and risk, and that have been previously mentioned in this dissertation. What I call the “discourse of normality” is shown to be prevalent among this sample, but also highly flexible. Through linguistic constructions that tag lived experience as “normal” or, alternatively, as deviating from that unmarked state, this discourse can function to either enshrine or erode the assumed isomorphism between normality and seronegativity. It can also be deployed in association with various moral subtexts, the only constant being the positive assessment of what is seen as normal. In the second section, delving deeper into discursive productions regarding HIV infection and risk, I offer a case study of one participant, Xavier. Trends in his usage of particular words and sentence structures are linked to broader dynamics of gender performance.
and stigma; they are also found to characterize the data as a whole. Consequently, in the third and longest section, I trace these patterns across couples, conducting a fine-grained linguistic analysis that reveals the existence of a collaborative, dyadic effort to construct and negotiate HIV risk. I call this the “semantic quarantine” and document its operation through three specific words: contaminar (to contaminate/infect), passar (to pass or give), and pegar (to get).

**Digging Deeper: The Discourse of Normality**

Members of HIV-serodiscordant couples in this research frequently made statements minimizing the import and experiential weight of HIV within their relationship. As Pamela stated, regarding Wilian’s disclosure of his seropositivity, “That didn’t affect our relationship.” Wilian characterized the couple’s collaborative approach to his ARV adherence as “routine.” Xavier and Juliana likewise rarely mentioned HIV unless prompted by me; they didn’t see it as one of the challenges they faced as a couple. The attempts at normalization Squire (2010) has identified in her work on HIV were also observed within this sample: both Adriano and Milene (seronegative members of couples that did not consistently use condoms) evaluated their partners’ health as being at least as good as their own. Adriano, for example, exclaimed, “Sometimes I’ll get a cold and I’m sick for longer than [Rita] is!”

Even couples who noted that HIV had impacted their relationship tended to describe its influence as fairly circumscribed. As noted in the couple sketch (see Chapter 5), Felipe compared the period immediately following Bibiana’s diagnosis to the couple’s current approach to HIV, saying, “We don’t talk about it much, actually, now that the situation passed—that first situation of finding out and everything.” Bibiana claims to only remember her infection in very specific situations, which included taking medication and using condoms. Jorge also reflected that the priority accorded to the virus had changed over time. In the not-too-distant past, Iara had
been very ill, but “now she’s getting back to normal. Now we’re going to think about other worries, like finding work and those things, you know?”

This last statement is just one example of a specific linguistic approach to HIV that I call the “discourse of normality.” Statements that can be seen as belonging to this discourse have appeared in other scholars’ data as well (e.g., Abadía-Barrero 2002; Boesten 2011; Polejack and Costa 2002; Reis and Gir 2009; Miranda et al. 2013), although, as noted in Chapter 3, they frequently do not receive much analysis (but see Knauth et al. 1998 and Persson and Richards 2008 for exceptions to this trend). Within this body of data, however, the frequency with which members of serodiscordant couples referred to things as “normal” suggested an emergent theme, and a code was created to tag these references. The memo in the latest iteration of the codebook for this research specifies this code is to be applied to talk that includes the word “normal,” whether in reference to HIV or other topics, as well as talk that clearly positions something as "normal" without using that particular word. This latter case—arguably a more ambiguous application of the code—usually involves clear juxtaposition of the "normal" with the "not normal." The hunch that something worth our analytical attention is going on in these statements is based on the idea that the normal aspects of life—while they differ from place to place and over time—are usually taken for granted, and therefore aren’t semantically marked in this way. That is, what is truly “normal” goes without saying—and certainly goes without having to call attention to how normal it is.

The application of this—admittedly—broad definition made “Normal” a very frequently-occurring code in the corpus of texts. With 86 coded segments, it was second only to “Economic Situation,” and on par with “Family” and “Biomedical Discourse” (codes applied to 85 and 84 segments, respectively). Within these 86 segments, however, a smaller cluster emerged that
shared a very specific focus. These 39 segments explicitly relate living with HIV/AIDS to “normal life.” Such statements seemed a propitious place to begin a close examination of the construction of HIV/AIDS among serodiscordant couples.

The distribution of utterances about “normal life” was not uniform across participating couples (see Table 6.1 below). Wílian and Pamela (the comment about the “routine” of ARV treatment notwithstanding) did not contribute any segments to this sub-group, with other couples contributing between one and 13 examples.

What is immediately apparent from Table 6.1 is that neither serostatus, nor gender, nor timing of couple formation, nor length of time since diagnosis, nor condom use neatly explains the variation in couples’ discursive production on “a normal life.” Although in general seropositive individuals tended to talk about this more than their seronegative partners did, roughly equal contributions were made by both members of the dyad in three couples (Wílian and Pamela, Xavier and Juliana, and Rita and Adriano). In addition, although women tended to account for more utterances than their male partners, that was not always so. In any case, my typically more frequent interactions with them, as well as the quality of the rapport I was able to achieve may have contributed to this. Regarding timing of couple formation and time since diagnosis, while the two couples who produced the greatest number of segments had been formed prior to discovering their serodiscordant status, and had only relatively recently received this news, Renato and Milene, who do not fit this pattern, contributed nearly as many utterances as Iara and Jorge and Bibiana and Felipe. Finally, both Wílian and Pamela and Bibiana and Felipe consistently use condoms, but the former couple said nothing about “normal life” while the latter talked about it 13 times.

For reference, this more restricted sub-grouping, if it were treated as its own code, would have been applied with the same frequency as the codes for “Preconceito” (Bias/Discrimination) and “Atendimento no [clinic name]” (Treatment at the clinic).
Table 6.1: Utterances of “Normal Life”

<table>
<thead>
<tr>
<th>Couple</th>
<th>Total segments contributed (# by SP*/ # by SN**)</th>
<th>Consistent Condom Use?</th>
<th>Couple formation pre-dates SP’s diagnosis?</th>
<th>Length of time since SP’s diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wílian and Pamela</td>
<td>0</td>
<td>Yes</td>
<td>No</td>
<td>&gt; 10 years</td>
</tr>
<tr>
<td></td>
<td>(0/0)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Iara and Jorge</td>
<td>11</td>
<td>Yes</td>
<td>Yes</td>
<td>&lt; 2 years</td>
</tr>
<tr>
<td></td>
<td>(9/2)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bibiana and Felipe</td>
<td>13</td>
<td>Yes</td>
<td>Yes</td>
<td>&lt; 2 years</td>
</tr>
<tr>
<td></td>
<td>(8/5)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Xavier and Juliana</td>
<td>1</td>
<td>No</td>
<td>No</td>
<td>&gt; 10 years</td>
</tr>
<tr>
<td></td>
<td>(0/1)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rita and Adriano</td>
<td>5</td>
<td>No</td>
<td>No</td>
<td>9 years</td>
</tr>
<tr>
<td></td>
<td>(3/2)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Renato and Milene</td>
<td>9</td>
<td>No</td>
<td>No</td>
<td>&gt; 10 years</td>
</tr>
<tr>
<td></td>
<td>(8/1)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*SP = seropositive partner **SN = seronegative partner

Considering this discursive production more closely also complicates the picture. There was a notable bifurcation of intent in these coded segments, with speakers either characterizing life with HIV/AIDS as (potentially) normal, or highlighting (even if inadvertently) deviations from normality. A handful of these utterances rejected HIV/AIDS as a source of fundamental difference outright. Milene, for example, dismissed the possibility that HIV treatment interferes
with normal life. She remembered dropping by the HIV testing center once, just prior to New Year’s Eve: “[Patients] were calling to see if, taking their medication like they should, they could drink [alcohol]. After one hour they could drink with no problems…so it doesn’t even hinder you in terms of drinking!” Her clear conclusion was that if people taking ARVs could drink like everyone else, then the treatment posed no significant limitations.

While only implicit in Milene’s comments, adherence to ARV treatment as the fundamental condition for living “a normal life” with HIV was foregrounded by both Adriano and Jorge. Adriano noted that, with respect to the quality of life possible to achieve as a person living with HIV/AIDS, “There’s a living example right here [gesturing to Rita]. You just have to know how to take your medicine and take care of yourself. You’ll have a normal life like anyone else.” Jorge, while positing adherence as slightly more challenging, agreed. He commented, “Both psychologically and physically, it’s difficult, but there are people who live quite well with this. Taking their medication and leading a normal life.” Bibiana (again, as noted in the couple sketch, see Chapter 5) reports feeling this is the overwhelming message propagated in online venues offering information and support to seropositive people. She notes that new participants are frequently in despair after receiving a positive HIV diagnosis. “[But] then all the testimonials come in from other people saying, ‘No, nowadays [an infected] person can have a normal life’ and what have you. So everything I read and see is much more positive than negative.”

In most of the commentary about normal life, the fundamental, though un(re)marked, point of reference for deciding what was normal was seronegativity (along similar lines as Persson’s initial discussing of the subject in her 2011 article on seronegativity). Sometimes this basis led to the explicit disqualification from normality of people living with HIV/AIDS, and
could be expressed quite bluntly. Juliana’s only statement on the subject is a clear example. In recounting the story of her daughter’s exposure to HIV (see chapter 5, also below), Juliana reports urging her to make it clear in court that the ex-husband “got HIV after you got together...You didn’t get married to him [knowing] he had it. You married him when he was normal, healthy.“ Although the nature of HIV/AIDS as a potentially hidden but nonetheless irrevocable mark of difference is generally much more subtle than in the above quotation, the majority of the 39 statements on normal life—often unintentionally—convey the same notion. Rita, Bibiana, Felipe, Renato and Iara all contributed such utterances; however, because of their fundamental similarity, only a few are discussed here.

Renato was prolific and patient with my questions about his comments on “normal life.“ As recounted in the couple sketch (see Chapter 5), when I asked him to explain what that phrase meant, he had said, “A life as though I didn’t have [HIV]. As though I weren’t seropositive.” Although he continually returned to his claim to have a normal life, in virtually every case, the subtext was “as normal as possible,” or “normal, in spite of HIV.” In one instance, I asked him how he felt about the care he received at the clinic. His response was: "For me, it's normal!...As you saw, right? My appointment [with the physician] doesn’t even last five minutes.” Renato thus constructs his scheduled follow-up appointments at the clinic as being just like any other medical check-up: when one is healthy, there’s ostensibly little to extend the process. What is left unsaid, of course, is that unlike most Brazilian men of his age—especially those not suffering from an obvious health complaint—Renato goes to the doctor at least four times a year. Whether the appointment itself lasts five minutes or 50, being seen by a physician is, as a gendered practice, only “normal” within the parameters of seropositivity.
Felipe’s frequent references to normality during his individual interview have also been previously noted. Here I merely want to point out that in every case included in the table above, he characterizes his life with Bibiana as something that can be “close to normal,” “practically normal,” or “normal, with limitations,” which is to say, not normal. This is made explicit in the following comment: “Everything comes with a price, you know, to pay for such a mess-up/carelessness. So I think it’s this, that [HIV] is something you can live with nowadays, without serious problems.” Whether the “problems” that arise from living with HIV are “serious” or not, they cannot be ignored and are constructed as a concrete result of past actions. The “price” one has to pay, precisely, is difference, the inability to live normally. Further, the word desleixo, while challenging to translate, is unmistakably negative, introducing connotations of ill-advisedness, even blame-worthiness.

This couple’s use of “normal” provides the opportunity to make one further observation. Bibiana, like her partner, frequently invokes this concept, and, like him, the totality of her discursive production leads one to conclude that she is (at least) ambivalent about whether this is truly achievable in the context of serodiscordance. Their talk gives the impression that “normality” and “difference” are in a tug-of-war. In contrast to Felipe’s usage, however, while Bibiana often positions herself as different from other people, whether in terms of health (because of HIV) or experience (because of her previous engagement in commercial sex work, for example), that difference has no moral overtones. Other examples offered in this section exhibit similar variation with regard to blame (contrast Jorge’s recognition of the laudable effort seropositive people expend in ARV adherence with Juliana’s clear association of HIV infection with immoral behavior). In summary, then, the discourse of normality is highly flexible. It can both assert and deny the potential for HIV-positive people to have lives just like those led by
seronegative people, and it can be associated with varying moral valences. Its occurrence indeed signals something deserving of analysis, but beyond making clear the desirability of “normal life,” and the likely juxtaposition of seropositivity with what is considered “normal” (not insignificant findings, in my view) it doesn’t illuminate any particular, inherent understanding of HIV. It also doesn’t tell us much about risk, or help uncover the process of situated negotiation within couples that brings these constructions to life.

Being that such questions lie at the heart of this research, however, further analysis is clearly warranted. D’Andrade (2005:90), speaking of cultural understandings, recommends that “it is better not to ask informants directly about their models, but rather to ask something that will bring the model into play, that is, something that will make the person use the model.” Accordingly, in neither the interview guide nor my more informal interactions with participating couples did I ask a question along the lines of “How do you understand risk for HIV?” Rather, I felt a particularly promising place to “see” these models in action would be through discussions about HIV transmission (and not about “risk” per se).

Therefore, as described in the Methods chapter, I drew from what I could discern as context-specific, taken-for-granted cultural knowledge about HIV and the risk of HIV infection to generate several vignettes. Then (although the follow-up questions were not phrased this way) I essentially asked my research participants to craft stories in response, that is, to make cultural sense of these hypothetical situations. In order to produce an answer about how infection occurred, or how the protagonist of the vignette was feeling, I reasoned, the participants would have to “use the model.” Working backward from their answers, I hoped to elucidate what Naomi Quinn (2005:17) calls “non-referential assumptions,” those cultural presuppositions that are not spoken, but nevertheless structure what is said. Indeed, I employed this approach in most
of the interviewing for this project, even when attempting to learn the “facts” about relationship history, HIV diagnosis, daily activities, and other basic information. Therefore, in the rest of this chapter, I treat participant responses to the vignettes and their articulations of their own personal experiences in the same way. This takes the form of paying close attention to particular words, sentence structure, and the variation exhibited in these regards by speakers over the totality of their talk. It also requires critical consideration of “narrative and narrative options not chosen” (Quinn 2005:32), hence, possible alternative framings, as well as silence, are prominent in the analysis.

Examining the whole of any participant’s talk in this study is a daunting task, given the multiple interactions envisaged by the research design. However, the case study approach is particularly suited for revealing the kinds of patterns of interest, since it “dish[es] up a big scoop of language—one we can be relatively certain will contain plentiful, rich clues to the topic under study” (Quinn 2005:16). As far as the mechanics of homing in on these “rich clues,” I have followed Gee’s advice: “Pick some key words and phrases in the data, or related families of them, and ask what situated meanings these words and phrases seem to have… given what you know about the overall context in which the data occurred” (2005:115). This method tends to produce voluminous write-ups of results, as the “building tasks of language” (Gee 2005, see Chapter 5 for review) are explored. Nonetheless, only the shortest case that illustrates patterns found to characterize the data more generally is presented here —largely because those patterns are so consistent across cases that, once understood, they can be more productively analyzed in a different format. Therefore, I first detail discursive approaches to risk through a case study of Xavier, focusing on what he says, how he says it, and what he does not say, as well as how those elements connect to some considerations already prominent in this dissertation—namely, gender
Discursive Approaches to Infection and Risk: Xavier as Case Study

For Xavier, HIV infection—like everything else in his life—is intricately bound up in his history of substance abuse. He consistently talks about his seroconversion as a product of previous carelessness, one way that he is now paying for past errors. In this sense, his discursive treatment of HIV and Hepatitis C (for which he is also positive) is the same. He claims to now “know better” than to engage in the behaviors that led to these infections, but learned this lesson “too late.” The main difference between HIV and HepC, for Xavier, is that the medication he takes for HIV is highly effective: he claims never to have been in ill health due to HIV. On the other hand, despite adhering to the difficult and months-long regimen required to cure HepC, the attempt was unsuccessful. Recent bouts of drinking have left him hospitalized for impaired liver function, and if an additional (postponed) round of treatment does not clear the virus, a liver transplant is Xavier’s only option. Hepatitis is much more problematic on a day-to-day basis for Xavier than HIV.

Nonetheless, Xavier sometimes uses HIV in our discussions as an enduring symbol of foolhardy past choices and his attempt to transcend them, the theme to which his narratives, sooner or later, always return. As such, the choice of which aspects of infection to foreground, and the language used to represent them, must be seen as strategic. When reflecting on how he may have contracted the virus, for example, he mentions only in passing that “we all shared things together back then”—a reference to needle/works-sharing. His emphasis, instead, is on his past unprotected sexual contacts, including both casual encounters and a relationship with a
woman who died of AIDS. Positioning his infection as sexually-acquired, he manages to highlight his sexual appetite and multiple partners—ways he previously embodied certain Brazilian dictates of masculinity—while minimizing the marginal aspect of his identity as a drug addict (“dependente químico”). In addition, he takes care to explain that condoms weren’t as readily available fifteen years ago as they are now, further normalizing his past sexual practices and, thus, infection.

The words Xavier uses to talk about the virus itself are also notable. Although most participants generally used the more common verbs passar and pegar (which can be translated in many different ways, but with reference to seroconversion, can be most faithfully rendered as simply “to give/pass” and “to get,” respectively) to discuss infection, Xavier’s verb of choice is adquirir, “to acquire.” More formal and specialized than pegar, adquirir was used one time apiece by three other participants, but only to refer to obtaining material goods. Xavier also uses the verb this way (twice), but he employs it three times to talk about becoming HIV positive. Twice this is in reference to his own seroconversion: “I think I acquired it a year before…” and “I could have acquired it…” while he once applied it more generally: “all the people who acquire this disease…” This is the more remarkable because it occurred in the context of Xavier’s diagnosis story, in which pegar figures prominently, via the phrase pegar o resultado, or “get/pick up the [test] results.”

Xavier does use pegar to talk about HIV transmission—but not in reference to his own case. During the couple’s joint interview, Juliana recounts the story of her daughter’s extended exposure to HIV, a result of her son-in-law disclosing his positive serostatus only when he feared he was becoming symptomatic. Juliana thanks God that her daughter did not seroconvert, and Xavier offers, by way of explanation for the persistent seronegativity: “She has blood just like
her mom’s; she doesn’t get [HIV].” This is a much more typical way to talk about seroconversion than Xavier’s references to his own infection, partially because *pegar* is a much more common word than *adquirir*, both among these informants and in spoken Portuguese more generally. Despite the difference in register, these constructions have an important element in common: that one can “acquire” or “get” something without necessarily seeking it. While both verbs denote being on the receiving end of an exchange, they allow the degree of involvement or intentionality on the part of the receiver to remain ambiguous.

This omission becomes visible as an important semantic choice when contrasted with Xavier’s use of the verb *procurar*, “to search for/seek out.” He employs this word one time apiece to talk about his own infection with HIV and HepC. In his reference to HIV, he explains that, at the time he seroconverted: “I was partying, I know that I asked for it, that I messed up…” Because *procurar* specifies active engagement on the part of the seeker, in this segment Xavier discursively accepts responsibility for his serostatus.

Returning to the previous examples and comparing Xavier’s word choice across various instances, a continuum of sorts emerges. In terms of attributing agency or responsibility for infection to a (potentially) seropositive individual, *pegar* requires the least intentionality or engagement on the receiver’s part. *Adquirir* may suggest a bit more (though, again, allowing this to remain ambiguous), but *procurar* leaves no doubt that active pursuit was involved.

Hence, it is significant that Xavier does not, for example, use this latter verb to talk about

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83 He also uses *procurar* in a similar way when talking about contracting Hepatitis C.
84 It should be noted that *pegar*, in general, is flexible, meaning it can be used for situations in which the receiver attains something after expending considerable effort, but also is employed for situations in which the receiver is taken by entirely by surprise. Several common usages of *pegar* support this assertion. The phrase *Peguei uma chuva*, for example, should be translated “I got caught out in the rain.” Likewise, *Ele pegou a mãe com outro homem*, is rendered, “He caught his mom with another man.” Neither of these instances (both drawn from interviews with this same group of participants) indicated intentional action.
Juliana’s daughter. Using *pegar* instead serves to reinforce the point of the story: that the daughter would not have been “to blame” had she become infected. The important but implicit corollary to this bears stating, however: HIV infection under other circumstances is something for which seropositive individuals can be held culpable.

Similar differences in meaning are present in Xavier’s direct statements featuring the verbs *contaminar,* “to contaminate or infect” and *passar,* both of which can focus attention on a source or sender, as opposed to a recipient. In explaining the process he went through to obtain his HIV test results, he told me, “I was already 90% sure that I was contaminated, I just didn’t have the courage to pick up the result, you know?” Even in the context of his diagnosis story, which contained a handful of notably formal or descriptive words (for example, “acquire,” “perish,” and “agonize”—as mentioned in the sketch of Xavier and Juliana, the former was a dedicated, effective storyteller), “contaminated” stood out as overtly negative and medicalized. While other words that are ostensibly synonymous, like *contagiar* (“to infect”) are sometimes used in positive, metaphorical ways (analogous to “infectious laughter” in English), I never heard *contaminar,* or any form derived from the same root (of which there are many in these data; therefore, for convenience, I represent as *contamin**) used to refer to anything but pollution and disease, usually with dire consequences.

Quite different is Xavier’s use of *passar.* Shortly after the excerpt quoted above, he transitions to talking about how his HIV diagnosis impacted him. He then outlines, and implicitly recommends, a way to continue on with life subsequent to being diagnosed: “It’s taking care, making a life, being sure to be honest, be careful not to pass [it] to other people.” With *passar* being linked to care, life, and honesty, the difference in overall tone is unmistakable. Further, it’s striking that Xavier chooses different words according to his role in
transmission. When he is the recipient, he uses *contamin*—albeit as an adjective, which emphasizes his condition of being infected, rather than the other person’s act of infecting him (which serves, in turn, to reaffirm his earlier acceptance of responsibility for his serostatus). On the other hand, when he is potentially the source of infection, in addition to urging efforts to prevent transmission, he employs *passar*, a much more ordinary and neutral word, which—again—serves to downplay marginal associations that might be evoked, particularly since he does not specify what one should “be careful not to pass.”

Tracing the total discursive production of one participant surrounding cases of HIV transmission—that is, taking a case study approach—enables making the type of comparisons mentioned above, and provides insight into the way that participant conceptualizes the virus. In this instance, the stories Xavier tells about his and others’ infection, as well as the particular words he uses, reveal that the meanings attached to the virus and its transmission are not static, but instead multiple and contingent. This close analysis thus complicates Xavier’s blanket claim that HIV is unimportant in his life.

Although the analysis is not presented, similar trends are apparent in the discourse of other participants. This suggests patterns in the way particular meanings of HIV are deployed, under given sets of circumstances. In order to most cogently consider this possibility, however, the analysis must now pivot in term of approach. Instead of exploring the topography of each individual participant’s discursive production about HIV transmission, cross-participant usage of a limited number of significant semantic features is mapped. The analysis moves from the least frequently-employed, but most “loaded,” to the most frequently-used and flexible terms, focusing on the words *contamin*, *passar*, and *pegar*, and seeking patterns in terms of who uses a particular word, in reference to whom, and in what context. Where the data support making
generalizations, these are outlined and archetypal quotes provided. “Negative cases” (Bernard and Ryan 2012:275), those that do not conform to a generally observed pattern, are also examined, although, in the interest of brevity, not every participant’s discourse will be considered in the same depth. Before presenting the analysis, however, the framework devised to explain the discursive production of study couples is outlined; this framework explicitly connects linguistic elements to notions of gender, sexuality, and stigma as they are expressed in affective, conjugal contexts. Applying this framework to the data from these HIV-serodiscordant couples reveals that an important aim of talk regarding HIV infection is to manage the degree to which each member of the dyad is discursively “exposed” to stigma, and to collaboratively construct a reality in which the meaning of risk in relation to a loved one is re-imagined.

**Semantic Quarantine**

Taken together, the totality of discursive production by this sample of HIV-serodiscordant couples suggests a collaborative, if unconscious, effort to minimize HIV-related stigma and call a context into being that allows theirs to be a “livable love.” These couples are aware that, in the view of biomedical and wider social discourses, they represent an immunological threat, and dangerous potential for moral contagion; to the degree that they have been shaped by and share these hegemonic ideas, to varying extents they, too, believe this. Yet the continuation of their union depends on, if not a strategic misrecognition of the virological state of affairs, then at least the exemption of themselves and their relationship from such associations. It is in light of this necessity that the highly selective and patterned use of discursive resources by these couples can best be understood. It is part of a suite of linguistic strategies by which they jointly create the conditions under which their bond is tenable.

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85 Other scholars have identified similar dynamics. For example, Ahearn (2001:129) discusses McDermott and Tylbor’s “collusional approach to understanding language and agency, which ‘refers to how members of any social order must constantly help each other posit a particular state of affairs’.”
Although only the terms contamin*, passar and pegar will be discussed in the remainder of this chapter, the analysis could well be extended to account for other practices, including the previously documented “discourse of normality,” as well as information management (Goffman 1963) with regard to serostatus.

Integrating these multiple strategies, members of serodiscordant couples enforce what I call a “semantic quarantine.” If “quarantine” is the “Enforced isolation or restriction of free movement imposed to prevent the spread of contagious disease” (www.thefreedictionary.com/quarantine, 7 Nov 2012), the isolation practiced by these couples is discursive: certain lexical elements (particularly those that are stigmatizing) are not allowed to “come into contact with” (that is, be used in reference to) that which the speaker wishes to protect from “infection.” Couples implement this quarantine with varying degrees of consistency and success. For some, there is significant “slippage,” meaning either inadvertent or intentional use of “nonsterile” linguistic constructions. For others, language and lived experience reinforce each other to the extent that their lives together effect a counter-hegemonic resignification of key practices and symbols. Regardless of whether the quarantine is successful, the purpose in each case is the same: to be recognized by others as a certain kind of “who-doing-what” (Gee 2005:23). More precisely, the goal is to preclude recognition of either partner as what Briggs and Mantini-Briggs (2003) call an “unsanitary subject,” and thereby avoid the symbolic violence such a stigmatized status can inflict on the constituent members of serodiscordant couples, as well as the relationship itself.

Before wondering, however, at all the effort expended to avoid symbolic violence, we should remember that discourse has the power to not only represent, but also construct our world (Gee 2005:210). Hence, these couples are concerned not only with symbolic violence
occasioned by the “wrong” recognition (although that is an important consideration), but also with the social and physical consequences that follow in its wake. João Biehl (2005a, 2007), Philippe Bourgois and Jeff Schonberg (2009) and Didier Fassin (2007) have all convincingly documented the physical impact of symbolic violence, with Fassin offering a particularly compelling example of the way a national history of oppression can be somatized in the bodies of individuals. Before jumping to a consideration of the possible consequences of a failure of the semantic quarantine, however, a more thorough accounting of its function is necessary. It is to that point the analysis now returns.

Words in Focus: Contamin*

The table below represents data on the least-frequently used, but potentially most powerful, discursive resource considered in this discussion, contamin*. Because it is fairly complex, and because I subsequently offer similar tables on the usage of passar and pegar, I explain the format briefly here. The left hand column contains what can be called “reference categories,” which stratify usage by who the speaker is talking about (self, his/her partner, or “others”) when using the word in question. The “others” category is broken down into two groups: fictional/unknown others, and people the speaker actually knows. The middle three columns (“speaker categories”) report the number of speech events produced by particular kinds of speakers for each of the reference categories. From left to right, these enumerate production by seropositive speakers, seronegative speakers, and the sum of those two groups. Given that these middle columns tally events, but not producers, the right-hand column shows how many unique speakers are responsible for the production in each of the reference categories, followed by a gender breakdown of those speakers. A quick example, for the shaded (orange)

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86 By “speech events,” I mean the number of separate times a term came up in conversation, which I find more informative than merely counting the number of times it was said. In making this distinction, my intention is to orient the count to packets of meaning larger than individual words.
Within this body of data, a total of eight speech events were identified in which contamin* was used to speak about “Others.” Of those eight speech events, equal numbers (n = 4) were produced by seropositive and seronegative speakers; only two of the eight events related to “Others” with whom the speaker is acquainted. Seven different participants (four women and three men) contributed to this total of eight speech events, meaning only one individual produced more than one utterance of this type.

Table 6.2: Usage of Contamin*

<table>
<thead>
<tr>
<th>Contamin*</th>
<th># of Speech Events</th>
<th># of Speakers (Gender)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>From</td>
<td>From</td>
</tr>
<tr>
<td>Usage refers to:</td>
<td>Seropositive</td>
<td>Seronegative</td>
</tr>
<tr>
<td>Self</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>3 speakers (3 males)</td>
<td></td>
</tr>
<tr>
<td>Partner</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>2 speakers (2 females)</td>
<td></td>
</tr>
<tr>
<td>Others**</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>7 speakers (4 F/3 M)</td>
<td></td>
</tr>
<tr>
<td>**Fictional/unknown</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>6 speakers (3 F/3 M)</td>
<td></td>
</tr>
<tr>
<td>**Known</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>2 speakers (2 females)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>9 speakers† (4 F/5 M)</td>
<td></td>
</tr>
</tbody>
</table>

† Column does not tally vertically because speakers contributed to more than one category

Although most participants (N = 9) did use contamin*, such uses were rare overall. The term was used roughly equally by seropositive and seronegative individuals, but usually (10/14 speech events) referred to someone other than the speaker. Within this “not me” subgroup of
utterances, we find contamin* most frequently applied to “others” that were either fictional, or with whom the speaker was not acquainted (6/10 speech events). Such statements were equally likely to come from either gender. Self-referential uses of contamin* were exclusively contributions of male speakers, two of the three of whom were seronegative. Uses of contamin* that referred to one’s partner came exclusively from female, seropositive participants. Female participants also applied contamin* to third parties they were personally acquainted with, while male participants did not.

In the discussion below, I provide and interpret examples for each of the reference categories in the table above. These sections are therefore titled: Contamin* in relation to others, Contamin* in relation to self (including sub-sections Contamin*: reading between the lines, which examines meanings evoked by the word, and connects it to the concepts of “unsanitary subject” and “sanitary citizen” (Briggs and Mantini-Briggs 2003); and Contamin*: the sound of silence, which explores why most seropositive participants do not use contamin* when they refer to themselves), and Contamin* in relation to partner. Throughout these sections, concerns that have already featured prominently in this dissertation once again prove relevant. The most important of these are normative Brazilian notions of gender (masculinity, femininity, and their complementarity), and the disciplining threat of HIV-related stigma.

**Contamin* in Relation to “Others”**

Participants most frequently used contamin* to refer to neither themselves nor their partners, but third parties. These uses included comments on specific cases of other seropositive individuals, generalizations about HIV-positive populations, and talk in response to fictional vignettes. To refresh the reader’s memory regarding this latter possibility: interviewees were asked to respond to one (or more) of three hypothetical scenarios involving HIV diagnosis,
followed by a standard set of questions regarding fictional characters’ feelings and previous and future actions. This format enabled participants to discuss HIV in a hypothetical context (i.e., without reference to themselves or their partners), but allowed the incorporation of personal elements if the speaker so desired (see Chapter 4 for a detailed explanation of this procedure).

Three uses of *contamin* occurred in relation to these vignettes. Felipe, a seronegative male, was asked to react to the scenario in which a woman is diagnosed with HIV as a result of routine pre-natal testing. This is exactly how his own partner, Bibiana, had been diagnosed. Perhaps because of this, he frequently makes explicit connections between his own experience and his analysis of the couple’s situation. However, the last question in the series prompted him to request clarification, which he phrased using *contamin*. After introducing this linguistic element, he ceases to relate the story to himself or Bibiana, despite the continued contextual possibility of doing so. I take this to indicate his desire, on some level, to avoid associating her with the connotations of that word.

Jorge, another seronegative male, also used *contamin* in responding to this vignette. The first question asked how the newly-diagnosed, pregnant protagonist was likely feeling; he answered that she was probably feeling scared and insecure, and especially afraid to tell her partner. He added that she might not be thinking clearly enough to remember that vertical transmission can be prevented, but “They have ways of not contaminating the baby and everything.” Unlike Felipe, Jorge’s experience of discovering his partner’s HIV status does not mirror this hypothetical situation. As might be expected, his responses do not create linkages between the two situations. In fact, the only time he leaves the frame of the story is to draw a contrast between himself and the male partner in the vignette, saying “I am not André.”

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87 Como pode ter acontecido tal situação? (“How could this situation have happened?”)
88 Como pode ter acontecido a contaminação dela? (“How could her infection have happened?”)
Iara, Jorge’s seropositive partner, also used *contamin*, although in response to a different vignette, this one involving a woman whose past sexual partner was a truck driver who began subjecting her to physical violence. Iara interrupted the short narrative several times to lament the main character’s choices and name the trucker as the source of infection, despite other possibilities. When asked how she knew this, she explained the events of the story as a consequence of this transmission, saying, “He’d already contaminated her.” She also implied that the trucker knew he was seropositive and did nothing to prevent transmission, at which point she began to excoriate him, calling him a “son of a bitch” and claiming she would prosecute him for his actions, were she in the female character’s place.

Bibiana used *contamin* to talk about HIV-positive individuals who not only did nothing to prevent infecting others, but actively tried to infect them. In the following quote, she describes communications regarding HIV from purportedly real “others” she’d seen in online forums: “They’re asking other people how they can contaminate someone, they want to contaminate the person they’re with.” She calls such actions “really selfish” and contrasts them with her own approach to her partner, Felipe, saying simply, “I don’t want [him to get HIV].”

Wílian and Pamela were less explicitly disapproving when using *contamin*, although both only applied the term in ways that clearly suggested HIV transmission should or could have been avoided. Like Bibiana, Wílian applied this term to a generalized group of “others” whom he didn’t know personally. For example, he noted that when he began going for annual HIV tests, in Porto Alegre, “There were lots of people contaminating themselves.” Similarly, in terms of making a general statement about HIV-positive people, Pamela explains the need for more HIV media campaigns targeting youth by saying, “Because there are young people getting contaminated, you know?” An interesting contrast in these uses of *contamin* is posed by the
different ways they use linguistic resources to construct agency on the part of seropositive populations. In the quote from Wilian, a reflexive pronoun is employed with the verb \textit{contaminar} to indicate that infection was something “people” were doing to themselves. Pamela, however, uses an adjectival form of \textit{contamin*} that simply modifies the noun “young people” without specifying any origin for the infections, or a responsible party. Such differences demonstrate subtle but significant possible variations in intended meaning, even within a cluster of terms that derive from the same root.

Although Wilian and Pamela frequently mentioned other seropositive people they knew, or knew of, the only instance in which \textit{contamin*} was used to refer to any of these cases involved a blood transfusion that occurred around 1989. Pamela claimed her nephew had received blood in the course of an emergency appendectomy, and “at that time there wasn’t this idea of, ‘Ah, I’m going to test this blood to see if it’s contaminated.’ They put contaminated blood in him.” Her nephew subsequently died of AIDS, which she related only after emphasizing that, “He didn’t drink, he didn’t smoke, he didn’t do anything…when they found out, it was too late.”

In this case, as with Jorge’s mention of the possibility of vertical transmission (above), \textit{contamin*} serves the purpose of marking the clinical nature of transmission, by virtue of which the listener is supposed to understand the newly seropositive individual as not to blame for his or her fate. Nonetheless, Pamela takes care to dismiss all other ways her nephew may have contracted HIV (an unnecessary endeavor for Jorge, since the subject of discussion is a newborn); all other modes of transmission are rendered literally impossible since, “he didn’t do anything.” Absent this medical angle, however, as illustrated by the foregoing examples,
participants’ uses of contamin* convey an undeniably negative assessment of HIV transmission, and culpability on the part of HIV-positive individuals who play a role in the process.

The last case of contamin* applied to third parties (i.e., not the seropositive participant or his/her partner) vividly demonstrates awareness of this perception. The speech event, while not particularly long, is incredibly rich, requiring a somewhat extended and complex analysis. I ask the reader to bear with the attempt to parse the relevant meanings. In this segment, Rita, a seropositive female, pregnant with her first child during this study, recounts a past decision to disclose her HIV status. At work one day, Rita’s boss had helped Rita to bandage a wound. Afterward, Rita felt obligated to reveal her serostatus to the woman, because, as she explained, “If a cut were to get in my blood, it contaminates, right? So those are things that I’m afraid of.” Although Rita’s phrasing seems awkward, it is not a simply a product of difficult translation, and it is not in error. It is indicative of underlying dynamics, to be explored below. What is immediately apparent in this segment, however, is Rita’s notion of herself as a source of infection. The linkage between this idea and the emotion of fear shows that she would feel responsible for an undesirable event coming to pass, if her boss were to seroconvert.

Returning to Rita’s phrasing of the mechanics of this potential transmission, what immediately catches one’s attention is the markedly involuted sentence structure. While it is possible to dismiss this as merely the occasionally-necessary awkwardness of repairing a false-start, before doing so, a critical consideration of the discursive work such a construction might be performing is warranted. A slightly longer excerpt is helpful in this regard:

Rita: ...I told her, because I was afraid, you know?
Shana: Afraid of...?
Rita: No, that she could have a...injury on her hand, because if a person has a wound, an open wound, you know? A cut, right? And if a cut were to get in my blood, it contaminates, right? So those are things I’m afraid of.
Note that, prior to specifying that an “open wound” or “cut” is necessary for transmission to occur, Rita had already begun a straight-forwardly constructed sentence. This sentence could have ended with something like: “If a person has an open wound, and my blood gets in, it can cause infection.” One primary difference between this more typical construction, and the way Rita chose to phrase the sentence lies in the subject choice for the key dependent clause. The direct, alternative phrasing “If…my blood gets in” makes Rita’s bodily fluids the subject, thereby grammatically ascribing agency to them. In contrast, Rita chooses “a cut” for the subject, which then requires the cut to take action (by “get[ting] in” to her blood), allowing her blood to take on a passive role. This feels counter-intuitive, not only because it is Rita’s blood that contains the agent necessary for potential transmission, but also because her blood, by being outside of her body, is occupying an unusual place—which would commonly merit some sort of semantic marking.

Another feature of Rita’s utterance that deserves attention is her use of contamin* itself. As the “motor” driving the process (seroconversion) that is the focus of Rita’s fear, the verb is clearly the most important part of the sentence. Yet it comes after the dependent clause, which focuses a listener’s attention on the specific conditions under which seroconversion can take place, instead of on seroconversion itself.89 Again, this may be interpreted as simply stylistic happenstance, but even if it is incidental, it does important discursive work. Namely, it communicates that Rita need not always be fearful regarding the physical aspect of her (non-sexual) relationships with other people: without an open wound, the infectiousness of her blood is constructed as irrelevant.

A further consideration requires an observation about translation, and one of the many ways it introduces challenges in analysis. While Rita’s utterance is rendered, “And if a cut were

89 For guidance on such slightly more technical, grammar-based analysis, see Gee (2005:182-193).
to get in my blood, it contaminates, right?” it should be noted that the “it” appearing in the English version is not actually present in Portuguese. The absence of a named subject is not, however, something extraordinary about this particular independent clause; it is a regular feature of the language Rita speaks. Indeed, because of the way verbs are conjugated in Portuguese (as well as Spanish, and other Romance languages), it is frequently unnecessary to explicitly include subject pronouns. A simple example can illustrate the point. The phrase “Usamos camisinha” is translated to English as “We use condoms.” However, because the verb form used (usamos) agrees exclusively with a first-person plural subject, the “we” in the Portuguese version does not have to be stated. It is, of course, possible to explicitly state the subject (Nós usamos camisinha), but doing so conveys a special emphasis on the subject (i.e., We use condoms—in contrast to people who don’t) that is not necessarily present in English.

Potential for ambiguity arises, however, when employing third-person verb conjugations, since the same ending can refer to, for example, “she,” “he,” or “it.” Without an explicit referent, a listener must rely on context to determine the source of an action. This is often relatively simple. For instance, the phrase, “A médica nos explicou sobre a camisinha. Disse que é para usar sempre,” is translated, “The [female] doctor explained to us about condoms. [She] said they should always be used.” It’s obvious in this case, though not stated, that the person who “did the saying,” so to speak, is the female doctor. But in Rita’s quoted statement, making such determinations is more difficult. When she says, “And if a cut were to get in my blood, it contaminates,” the thing which contaminates could be either her blood or the other person’s cut. Both are third-person singular subjects; hence, both agree with the third-person singular conjugated form of the verb that Rita uses. If anything, a listener may be more apt to link “contamina” to the cut, since the cut was the subject of the preceding clause. Rita’s
phrasing, therefore, makes use of the linguistic resources of Portuguese to allow the agent responsible for contamin* to remain ambiguous, discursively distancing herself from this undesirable identification.

From an epidemiological or biomedical perspective, of course, there is no such ambiguity. Had the boss (assuming her seronegativity prior to this exposure) seroconverted after helping to bandage her employee’s wound, Rita would have been identified as the source of infection. And, as mentioned above, it is evident that Rita herself does recognize this. In fact, the point of her story was that she had done everything in her power, including opening herself up to discrimination by disclosing her serostatus, to prevent her boss from becoming infected—actions which make no sense if she is not aware of her infectivity. Yet, discursively, she goes to great lengths to avoid unambiguously stating as much; essentially, Rita refuses to enshrine her biomedical understanding of the situation through grammar. Such an interpretation is supported by the further observation that all of this talk can be seen as a detour that allows Rita to bypass the most direct possible response to my initial query. When probed for details on what, precisely, she feared sufficiently to compel the disclosure of her serostatus to her boss, Rita could simply have said, “Infecting her.” But to do so might require her to use contamin* in reference to herself, which she seems determined to avoid.

Contamin* in this body of data was most frequently applied to “Others.” The variety exhibited among these uses brought to light an important characteristic of the term: its bifurcated meaning. On one hand, in some of the examples above, the medicalized ring to contamin* connotes a clinical context of HIV infection, and the infected party is seen as a victim. Transmission stands as proof of failure of a technical sort; hence the party responsible (when specified) may be seen as incompetent (or ignorant, as in the story about Pamela’s nephew).
the other hand, outside of clinic contexts, the word conveys an unmistakably condemnatory tone. Employed in this way, it foregrounds not only the notion of “HIV-positive person as an infectious agent,” but also the immorality of behavior on the part of seropositive individuals that results in transmission.

*Contamin* in Relation to Self

Self-referential uses of *contamin* were far less frequent than applications of the term to “others.” This reticence was particularly notable among seropositive participants. Although they contributed half of the 14 speech events involving *contamin*, only one of these instances referred to the seropositive speaker. Seronegative participants linked themselves to the term three times. The reasons for, and implications of these patterns of use/non-use are explored in this section.

Xavier was the only seropositive participant to apply *contamin* to himself, and he only did so once. As the case study makes clear, he typically used other words (especially *adquirir*) to refer to his infection. Therefore, two questions demand answers regarding his use of the term. First, given the negative connotations associated with *contamin* (demonstrated both through documented uses of the term and other seropositive participants’ avoidance of it), why would Xavier use it to talk about himself? Second, why did he only employ it once? In essence, we must ask: is there something special about Xavier that allows him to use the term when others cannot or will not, and is there something special about the context of his single usage that allows him to use it when he cannot or will not under other circumstances?

The answer to both questions is yes, and they are linked. Like most of Xavier’s stories, the explanation has to do with his identity as an (ex-)*dependente químico*. As demonstrated in the case study, he presented his HIV infection as sexually-acquired, rather than IDU-related,
because this allowed him to evade some of the most stigmatized associations with the virus, emphasizing instead an appropriately sexual, masculine gender identity. Nonetheless, he also unequivocally “owned” his infection, that is, stated that it was the result of his own ill-advised past choices. He was the only seropositive participant in this study to do this. In answer to the first question posed in the preceding paragraph, then, his orientation to infection is what differentiates Xavier (i.e., makes him “special”), and enables him to use \textit{contamin*} when other participants do not; he accepts the responsibility for infection the term implies.

But it is a circumscribed acceptance. Overall, Xavier worked quite diligently to distance himself from the kinds of choices he had made in the past—and, therefore, the kind of person he demonstrated himself to be. With every narrative that featured his current, disciplined and reflective struggle against addiction, he showcased actions and attitudes he would not previously have taken, constructing himself as a new kind of person, reborn. Discursively speaking, after loading the blame and shame associated with seropositivity onto his previous self, he kills it off, emerging from the ruins as a new self “clean” of such stigmas. Thus, when he says, “I was already 90\% sure that I was contaminated,” it is not incidental that he is talking about “the old Xavier.”\textsuperscript{90} In contrast, his uses of \textit{adquirir} in relation to himself occur in the context of more present-centered discussions. In answer to the second question, then, we can say that what is “special” about Xavier’s use of \textit{contamin*} (and other words like it) is that it refers to a constellation of actions and values that Xavier has disowned. He uses other words when he wishes to index his current self.

The other instances in which \textit{contamin*} was self-referential come from male, seronegative participants, Adriano and Felipe. Felipe, who had picked up his partner, Bibiana’s,

\textsuperscript{90} Likewise, when he uses \textit{procurar} (“I was partying, I know that I asked for it, that I messed up”), it is in reference to the things he used to do that he doesn’t do anymore.
HIV result at a private laboratory, uses the word as he describes the mental “block” that led him to focus, at the time, exclusively on helping Bibiana assimilate the news: “Even when I could have been contaminated, I didn’t…I didn’t think much about that.” Whether this statement accurately represents his mindset in the immediate aftermath of the diagnosis or not, he did subsequently “think about that” enough to undergo at least three HIV tests, and he seems to view his continued seronegativity as stroke of luck almost too good to be believed. Although he repeatedly claims that HIV-positive individuals can have a (close to) “normal” life (see first substantive section in this chapter), his use of contamin* to describe a condition he feels he narrowly escaped might be seen to belie these assertions.

Adriano’s uses of contamin* also unambiguously communicate the desirability of avoiding HIV transmission. In explaining why he thinks he has not seroconverted (despite repeated past and present exposures through unprotected sex with his partner, Rita), he says, “It seems like this [by which he means his lack of concern about/discrimination based on HIV status, along with his love for Rita] is making it slower that I get contaminated, understand?” Thus, Adriano pits love and respect for his partner against “contamination” with HIV, clearly demarcating an immunological battle between good and bad. The other time he uses this construction to refer to himself, he muses to Rita: “Let’s suppose that I come to contaminate myself. Of course I’m not going to blame you, but you’re going to feel guilty.” In this sentence, it is again understood that HIV transmission is something for which someone may be blamed or feel at fault; hence, it is clearly viewed negatively.

One notable linguistic feature of this second occurrence is the use of a reflexive pronoun with the verb “contaminate.” As described above, with reference to Wílian’s use of this construction, such pronouns indicate an action done by someone to him or herself. In this case,
because Adriano uses the first person forms, it denotes infecting himself. Grammatically, he could easily have constructed a sentence that leaves the source or agent responsible for his “contamination” unspecified, as he does in his first use of the verb (“I get contaminated”). Alternatively, he could have identified Rita as the source of his hypothetical infection—the unvarnished epidemiological truth of the situation—saying essentially, “Let’s suppose you come to contaminate me.” Instead, he linguistically assumes responsibility for his exposure and potential infection. This serves two purposes: it reinforces the spoken message that Rita will not be blamed for transmission, and it constitutes a limited refusal to discursively link her to the negative, medicalized, contamin*.

Given these connotations, why do Felipe and Adriano use this term in reference to themselves? They are clearly not effecting the kind of discursive rebirth in which Xavier is engaged. Since none of the three seronegative female participants used contamin* in this way, it may be that gender is an important consideration. In addition, something Felipe and Adriano have in common is an extended period of exposure to HIV via their current partners. For Felipe, this occurred prior to Bibiana’s diagnosis. Adriano, on the other hand, was aware of Rita’s serostatus from the outset of their relationship, but continues to be exposed through unprotected intercourse.

Instead of interpreting their seronegativity in terms of probability or even luck, though, both men suggest that some special kind of resistance to HIV has prevented their seroconversion. In recounting his experience with HIV testing, Felipe notes, “I was always calm. The first test I was maybe a little bit nervous, but for the others I was calm. It seemed I knew that I didn’t….it could be that I have some kind of resistance.” Whereas the “resistance” Felipe invokes is primarily of the immunological sort, Adriano takes a more holistic approach. In the segment
quoted above, he suggests that the strength of his love for Rita protects him from, or at least slows down the process of, infection. At a later date, he elaborated on this point, saying, “I think the Man upstairs [prevents me from getting infected]…, my dedication to her, my caring, these things make it so that—And another thing: I don’t have it stuck in my head all the time.”

From the perspective of these two seronegative men, “resistance” can be seen as an outgrowth of the strength, invulnerability, and (particularly relevant in Adriano’s case) risk-taking that are fundamental to Brazilian masculinity (Ford et al. 2003; Knauth 2007). To this strength, Adriano adds his lack of inclination to worry (which no risk-taking, invulnerable man needs to do—worrying is feminine), and God—the ultimate patriarchal authority in Brazil. As such, these statements adapt norms for gendered performance to the men’s own lived experience. Precisely because their serostatus supports (or, at least, doesn’t contradict) their construction of themselves as “resistant” and strong—that is, normatively masculine—using contamin* with reference to themselves actually serves to emphasize their invulnerability.

**Contamin*: Reading Between the Lines**

As suggested previously, and further supported by the foregoing examples, it is difficult to use contamin* without invoking notions of responsibility—if not blame—for transmitting the virus. The word therefore connects to both historical and contemporary assignations of stigma. Historically, since—in Brazil, as in the U.S.—the virus was first characterized as occurring among certain populations (MSM, IDU, CSW), an HIV diagnosis came to be seen as indicating membership in those groups. Because those groups were considered morally transgressive—and hence, stigmatized—HIV absorbed stigma by association. Despite many participants’ aforementioned assertions that “anyone can get HIV,” ideas associating infection with deviance persist, both in society generally, and among seropositive individuals themselves. Even those
who claim to reject such conceptions, however, apply contamin*—with all its negative connotations—to situations in which HIV-positive people intentionally engage in behavior that makes transmission possible. This is because, ethically and to some extent legally, those who know they have the virus are seen as responsible for stopping its spread. Many participants spontaneously mentioned the law criminalizing intentional transmission, which they interpreted as requiring consistent condom use, or at least disclosure of serostatus to partners.

Legal considerations aside, however, participants clearly saw compliance with current biomedical mandates (including the prohibition of sexual contact without a condom) as necessary to avoid being marked as what Briggs and Mantini-Briggs (2003:xvi) call “unsanitary subjects.” As these authors note, such people are “judged to be incapable of adopting [the] modern medical relationship to the body, hygiene, illness, and healing” (Briggs and Mantini-Briggs 2003:10). Individuals may come to be considered unsanitary subjects in at least two ways relevant to this study. First, they may belong to a group that is viewed as threatening, rejecting, or otherwise disrupting this relationship. I would argue that all of the historical “risk groups” in the Brazilian context—MSM, IDU, CSW, and, more recently, the poor—are seen in precisely this way, largely as a result of “improper” uses of the body. This means that, absent evidence to the contrary, members of such groups are de facto unsanitary subjects.

The second way one can be ascribed such a status is to demonstrate, whether intentionally or not, that one cannot or will not subject one’s own body to this relationship with modern (bio)medicine. Skipping medication, or not using condoms, for example, might be seen as such a demonstration. For HIV-positive individuals, then, using condoms and ARVs, adhering to dosing schedules, keeping medical appointments, submitting to routine testing, and understanding modes of HIV transmission, as well as the meaning of CD4 and viral load results
are not merely instrumental in maintaining health (and, incidentally, this is precisely what is conveyed through the “adherence clinic” appointments discussed in the Setting chapter). These artifacts, practices, and knowledge are also symbolic of having transcended the status of unsanitary subject for “sanitary citizen” (Briggs and Mantini-Briggs 2003:10).

How an individual is classified is of great consequence. Unsanitary subjects are seen as “threats to the health of the body politic” (Briggs and Mantini-Briggs 2003:xvi), which confers a stigma that can be associated with, but is distinct from strictly HIV-related stigma. Sanitary citizens, in juxtaposition, are lauded by the biomedical practitioners that attend them, and as Biehl (2007) suggests with reference to patient-citizenship, may use this identity to counteract HIV-related stigma. The importance/meaning patients in this study attach to such approbation or denigration may be indicative of their underlying conception of their relationship to the health system, and as such may substantially impact their communication with the clinic personnel. This will be discussed in the conclusion to the dissertation. For now it is sufficient to reiterate that, while it is theoretically possible for any individual to achieve an identity as a sanitary citizen, certain stigmatized groups are typically seen as virtually synonymous with HIV infection, as well as considered *de facto* unsanitary subjects.

*Contamin*:* The Sound of Silence*

Because *contamin* taps into these meanings, it is perhaps not surprising that, for reasons outlined above, among the seropositive participants, only Xavier used this term to talk about himself. But because silence—particularly a very specific silence, like this one—can communicate as effectively as words do, it’s important to critically examine the non-use of this term. Focusing on what occurs in place of *contamin* reveals that other seropositive participants
invested heavily in strategies that differed from the one Xavier employed, but nonetheless were similarly intended to discursively distance the speaker from the type of behavior or identity contamin* can evoke.

Wílian, for example, claims he was infected through what he portrays as normal, male sexual behavior. This includes multiple, one-time or casual partners. He says, “I was single for seven or eight years. You know how single men are—they go out with one woman, then go out with another, right?” He says he has no idea who might have given him the virus; even just with reference to the women in his neighborhood, he characterizes his sexual activities as a “clean sweep” (lit. faxina, house cleaning), which conjures notions of masculine sexual insatiability (the more, the better—i.e., the more masculine).

It should be noted that while Xavier also claims heterosexual contact as the mode of transmission, he admits other possibilities (i.e., IDU) and acknowledges his personal agency as generating his exposure. Wílian’s discussion of his own case, in contrast, acknowledges no other potential routes of exposure, and naturalizes his sexual behavior to a degree that obscures his own decision-making/agency. What the two men’s portrayals of their exposure to HIV have in common is their grounding in valorized, masculine identities. Since both lack access to the economic resources that would allow them to enact such identities through the provider role (Gregg 2006; Ford et al. 2003; McCallum 1999), they are largely limited to performing masculinity via sexuality. In reference to themselves, then, they evade HIV-related stigma by tracing infection to what one simply “must” do as a man. The use of contamin*, with its strongly negative connotations, would undercut this discursive strategy.

Iara, Bibiana, and Rita also claim unprotected heterosexual contact as the route of infection, but—significantly, and in contrast to the male seropositives examined thus far—each
takes care to name a limited number of partners from whom they might have contracted the virus. This should be seen as their attempt to claim a modicum of adherence to cultural norms for appropriate female sexual behavior (Goldstein 1992, 1994; Scheper-Hughes 1994; McCallum 1999), thus exempting them from the full weight of reprobation directed at the stigmatized groups associated with *contamin*, especially commercial sex workers.

Iara, for example, acknowledges her multiple sex partners, but implies that her behavior, which some might label “promiscuity,” is qualitatively different from that of CSWs. She goes so far as to employ them (using a term I had never heard before, suggesting its politically-incorrect nature) as a foil to accentuate her own sexual decorum. She confided that, after suffering a miscarriage and having her heart broken by a long-time partner, “the odds were stacked for me to become a whore,” but she simply could not bring herself to earn a living that way. In essence, she admits considering this possibility only the wake of near-total emotional devastation, but insists that she is not “that kind” of person. In terms of Gee’s (2005:23) “who-doing-what,” she dissociates herself from such an identity, and the stigma that stubbornly adheres to it. In essence, she resists, not by questioning the moral valence associated with CSWs, but by claiming that an HIV infection does not necessarily indicate membership in a transgressive group. “Good” women can get HIV, too.

Bibiana also attempts to discursively evade HIV-related stigma, even though she actually did support herself, her partner, and their child through commercial sex work, and despite the probability that she contracted HIV from one of her clients. Interestingly, her strategy for doing so relies on the success of rhetorical moves like Iara’s. If it’s true that sexually-upstanding women contract HIV along with their morally-suspect sisters, then, Bibiana argues, there’s no reason for an HIV diagnosis to confer stigma at all. This is explicitly stated when she discusses
why she’s more concerned about someday disclosing her past sex work than about revealing her serostatus to her daughter, who is still quite young: “Because the disease—I can be a nun, have sex with someone once and get it. Like, ‘Your mom is practically a saint and she’s sick’....I could have gotten it from [my daughter’s father], just like I could have gotten it [from a client], you know?” She goes on to speculate that acceptance of her HIV status will be relatively unproblematic, because “disease” is “normal,” but fears that without a careful explanation of the context of her decision to engage in sex work (economic necessity and the moral responsibility to support her child), her daughter may reject her.

Rita, like Iara and Bibiana, claims to have been infected via heterosexual transmission, although she says she doesn’t know by whom. Unlike the other two seropositive women, however, she can count her pre-diagnosis sexual partners on one hand with fingers to spare, and her conception of appropriate feminine sexuality differs from Iara’s and Bibiana’s by not “pushing the envelope” on how many partners are acceptable. In fact, having had multiple sex partners is not something she defends, largely because she constructs this behavior, not as a choice, but as something compelled from her. It was revenge on her first sexual partner, a man fourteen years her senior, who, over the course of their six-year relationship, deeply wounded her with his periodic infidelities and postponement of their marriage. She suspects he did not use a condom in his affairs, resulting in her exposure to HIV and subsequent seroconversion. She goes on, nevertheless, to disclose that she had other, unprotected sexual contacts, saying, “It was after many years of—I think that after [my long-term boyfriend] misbehaved so much, did so many things, the mistakes he made, you know? I…I…I hooked up with two men after that.” This was part of the complex unraveling of what she calls “blind love,” which she says “destroys many people and causes a lot of hurt.” In response to my query as to why she decided to forego
condom use in these one-night stands, she says, “In truth I was a child still. Nineteen, 20 years old. I was just learning the ropes of life, you know?” In other words, she was too hurt and too young to know better.

Because she positions herself primarily as a victim vis-à-vis HIV infection, Rita could use *contamin* as a discursive weapon against men she clearly feels have wronged her, saying something along the lines of “One of them contaminated me.” But, given the lack of a cure for HIV, such a construction would also taint her. Instead, she opts to portray her past self as sexually-inexperienced and emotional, thus foregrounding her identity as a “good woman.” This allows her to make use of traditional gender norms as a shield from the brunt of HIV-related stigma. Overall, despite differences in Iara, Bibiana, and Rita’s portrayals of their paths to HIV infection, the discursive strategies they use to minimize stigma are anchored in the same cultural ideals about female sexual behavior, a foundation *contamin* would serve to erode.

Renato can be seen as the seropositive participant with the most justification, and least potential discursive risk, for employing *contamin* in reference to himself. According to him, when he was tested for HIV, he had not been sexually active and had never engaged in injection drug use. In addition, he was too old to have been exposed as a baby. He had no identifiable risk factors, but a persistent herpes outbreak suggested he was immunocompromised. It was only after he was diagnosed with HIV that his mother remembered a possible route of exposure that occurred during a previous hospitalization in the interior of the state. He says, “Mom saw that they used a glass syringe. It was in [a city in the interior]…But we paid no heed then. The test came out positive and that’s when I remembered that syringe.” Thus, Renato claims he was infected through what would commonly be described as “contaminated” injection equipment in a health care setting.
A use of *contamin* in this context would highlight the clinical nature of his exposure, recalling Pamela’s recourse to the term when referring to her nephew who contracted HIV through a blood transfusion. It could also implicitly assert his blamelessness in regard to seroconversion. But Renato never uses that word—or any word to describe how he acquired HIV; re-reading his narrative reveals that the moment of transmission is completely elided. Indeed, without knowledge of the ways HIV can be transmitted, his statement quoted above would be mystifying, since it forces the listener to fill in the connection between the “glass syringe” and Renato’s subsequent serostatus. Although this reticence could be due to many factors, given Renato’s prolific use of “normal” to describe his life (see couple sketch and first substantive section of this chapter), it seems defensible to suggest that leaving the mechanics of his infection implicit is a way of minimizing its import. Specifically, he may reject *contamin* for the same reason that Rita potentially does: avoiding it allows him to emphasize a different identity, in his case, as “normal” person.

We’ve seen that nearly all of the seropositive participants in this study refrain from applying *contamin* to themselves, and explored ways this avoidance supports their projects of presenting a particular kind of self. In particular, I argue that they are aware of the stigma attached to their serostatus by virtue of its association with groups seen as “deviant,” as well as the typical conflation of membership in historical risk groups with the status of unsanitary subject. In response, most portray themselves as laudably performing other identities—exhibiting characteristics that mark them as falling well “inside the fence” in terms of gendered respectability. As such, they stake claims designed to invalidate their *a priori* classification as unsanitary subjects. Because their serostatus leaves them always vulnerable to such interpretations, however, words like *contamin* are, in general, too dangerous to use; they are
linguistic IEDs, capable of causing unpredictable explosions and inflicting grievous discursive harm.

**Contamin* in Relation to Partner**

At this point, it’s germane to note that, while most (N = 4/6) seronegative participants used *contamin* to refer third parties, not one of them ever applied it to his or her seropositive partner in my presence. Though they clearly understood the potential consequences of maintaining a sexual relationship with a seropositive individual, and did sometimes talk about the eventuality of their own seroconversion, uninfected partners never expressed this possibility using *contamin*. Hence, because neither the issue, nor the word was completely taboo, we must ask what prompted seronegative speakers to so assiduously prevent this intersection. The instances in which they did use *contamin* (discussed above) demonstrate that they share their partners’ awareness of the medicalized, stigmatizing nature of the word, as well as their generally negative judgments about HIV itself (often despite their recourse, on other occasions, to the “discourse of normality”).

This means that referring to a loved one with *contamin* would effectively name him or her as an unsanitary subject—immoral, dirty, and unmodern—both by highlighting presumed membership in a stigmatized group, and by raising the possibility that s/he might behave in ways (in this case, unprotected sexual contact) that would necessitate disqualification from “sanitary citizen” status. Such naming would introduce (or, perhaps more accurately, acknowledge) a tension into the relationship that would be exceedingly difficult to reconcile with the day-to-day experience of couplehood, which most participants described as including interdependence and companionship (see also Maksud 2002). The avoidance of *contamin* thus constitutes a highly
significant silence, because it elides precisely the association that is most threatening to a serodiscordant relationship.

That being the case, the fact that two seropositive participants used contamin* in relation to their seronegative partners may appear to put the entirety of the foregoing analysis in jeopardy. Such usage would seem to be the ultimate case of the proverbial pot calling the kettle black. However, attention to context reveals these two instances to be assimilable within the explanatory framework elaborated thus far. It bears asserting, though, that “context” must be understood in two different senses: narrowly, in terms of how the word is deployed within a narrative, and broadly, in terms of the ethnographic context in which the entire conversation—and indeed, the relationship itself—takes place.

Both meanings of context are relevant to interpreting Iara’s application of contamin* to Jorge. She had been regaling me with the story of Jorge’s initial resistance to condom use, after they’d learned of her serostatus. As mentioned in the corresponding couple sketch, he’d expressed wanting the two of them to be “the same,” but she claimed to have roundly rejected this “craziness.” Her efforts to persuade him to accept condoms included projecting the potential consequences of his attitude into the future: “I said to him, ‘I’ll go and you’ll be here, contaminated; you’ll be all alone.’” In this sentence, “go” is a euphemism for “die”—remember that Iara was gravely ill at the time of her diagnosis, spending almost a month hospitalized. Given that background, raising the specter of her own death is not the histrionic resort to extremes it might otherwise seem to be. Rather, it simply evokes a future both partners admitted they had thought possible. Iara asks Jorge to think through the seroconversion he claimed, at the time, to welcome, and contemplate what it would mean in the event that he found himself single.
again, after her death. She implies that, being “contaminated,” it would be impossible for him to find another partner.

There are two angles from which to consider this use of contamin*. The first, and perhaps more immediately apparent, is as it applies to Jorge. From this perspective, Iara constructs a hypothetical future situation in which Jorge is “contaminated,” and suffering the negative consequences of occupying such a stigmatized subject position. She claims that his serostatus will, in essence, exclude him from the benefits Brazilian men traditionally expect to gain from stable relationships with women, which Jorge himself had previously described to me as including companionship, having someone to take care of the house and his needs while he worked outside the home, and sex. The message is: You will have no one to take care of you. As Iara tells the story, however, this emotionally and socially catastrophic denouement can be circumvented by adopting condom use. Thus, she uses the full, negative weight of contamin* to convince Jorge to avoid potentially becoming an unsanitary subject.

The second angle also links contamin* to classification as an unsanitary subject, but implicitly, and in reference to Iara herself. If Jorge refuses to use condoms, then, of course, to the extent that the couple remains monogamous, Iara cannot use them either. Through exposing her partner to HIV, she would find herself in a position somewhat similar to that of the trucker from the vignette, whom she so openly censured, as previously detailed. Clearly, such behavior is anathema to her, perhaps precisely because it opens her up to classification as an unsanitary subject—the kind of person who would knowingly infect his or her partner. Hence, in addition to telling Jorge that condom use is in his long-term interest, she may also be suggesting that his refusal confers an identity on her, as a source of infection, that she is striving to evade. Because
Jorge does reconsider, both members of the couple are relatively insulated from such characterizations.

The discursive lengths to which Rita has gone, in an effort to insulate herself from contamin*’s connotations, have already been discussed. So it may seem counter-intuitive that she would apply the term to her partner, Adriano. But, as with Iara’s usage, on closer inspection, the situation becomes much more complicated. I had asked Rita what her greatest worry had been, over the previous week, and she—unlike any other participant—had prioritized stress over Adriano’s potential seroconversion. After an extended discussion, that included a long tangent about the health of the baby the couple was expecting, I asked her, “There’s never been a time that everything—that you, like, forget [about your serostatus]?” She said no, and began to explain why:

Rita: There was a situation, about—some time ago, a situation that happened. It was... (sighs) It was one time that he drank too much, you know? And he commented about this, you know? If one day he got contaminated. I know he was drunk.
Shana: But, then, what would he do [if he seroconverted]?
Rita: But the sub—No, it was his subconscious talking, ok? That it would by my fault.

That hearing this from her partner had been difficult for Rita was evident from her comportment as she recounted the exchange. She acknowledged that its impact, at least on her, had lingered. Eventually, it had come up in conversation, though Adriano had no recollection of what had happened. After hearing what he’d said, Rita claims her partner had been speechless, hung his head, and said he was too ashamed to look her in the eye.

One aspect of Rita’s use of contamin* that must be noted, then, is that she was using it, not in spontaneous reference to Adriano, but to report some of his past speech about her. Hence, two possibilities arise. One is that she is reporting her partner’s speech verbatim—meaning that
he really did use *contamin* in reference to her. In light of his other, already reported, uses of the term, this seems plausible, but there is no way to know for certain. Fortunately, this is scarcely important, since the other possibility is that Rita is reporting a paraphrase of Adriano’s utterance, using words intended to convey how what he said made her feel.

What she reports feeling was fear for the continuation of the relationship, which accords exactly with the explanation offered above as to why seronegative partners would normally avoid using *contamin* specifically, and why the semantic quarantine is necessary more generally. Using such a stigmatizing term in relation to one’s partner does destabilize the couple’s bond. Additionally, Adriano’s reaction, upon hearing what he said, demonstrates that he, too, recognizes the gravity of his words. The normally voluble jokester falls silent, unable to raise his eyes.

Still further support for this conclusion can be found in the way Rita situates Adriano’s comment. In potentially the most revealing aspect of this exchange with me, she offers two different reasons why her partner’s utterance is not as damning as it might appear: he was drunk, and it was his subconscious speaking. Thus, although it is her choice is to relate this story, even as she tells me what Adriano said, she simultaneously claims it wasn’t really him that said it, “Because our subconscious is one thing, you know? And the person himself is another.” This interaction with her partner was of such consequence that, in the context of explaining their relationship, she could not avoid telling it. Yet since the threat of dissolution of their relationship appears to have passed, it is equally essential to exclude those words, and the implicit judgment of her they convey, from having any connection with their present lives.

To summarize this section, if we suppose, as many participants in this research unequivocally stated and feared, that HIV/AIDS remains heavily stigmatized in Brazil, and that,
as outlined in the section above, *contamin* is likewise associated with pollution—both immunological and moral—then both the particular uses to which the term is put, and the relative paucity of its use overall, become understandable within the framework of the semantic quarantine. *Contamin* calls to mind stigmatized identities, in the mold of Briggs and Mantini-Briggs’s unsanitary subject, with which members of serodiscordant couples are all too familiar. Applying a term like this can be seen as a type of symbolic violence (with potential biological ramifications) that those who perceive themselves as vulnerable understandably wish to avoid. Hence, nearly half of all uses of *contamin* in this body of data refer to fictional or unknown “Others.” There were comparatively few self- or partner-referential utterances containing this term. In its place, many participants (but especially those with the virus) presented themselves in terms of other, socially-valorized identities, particularly gender.

**Words in Focus: Passar**

*Passar*, in the particular sense relevant to this study, was used by most participants (N = 10), and much more frequently than *contamin*, being employed in 30 speech events (vs. 17, i.e., nearly twice as many). One caveat with regard to meaning/counting bears stating here, however. *Passar*, in contrast to *contamin*, is a common word, used in several different ways. Among these are meanings that would normally be translated to English as “to happen” and “to go through.” Such uses do not figure in the numbers provided above. The inclusion criteria for uses of *passar* in those counts require the word to mean “pass,” in reference to a disease or infection. Although the same flexibility was employed when counting uses of *contamin*, that term was applied exclusively to HIV infection. In contrast, *passar* was used by Pamela, a seronegative female, in two speech events to talk about the shame and anger she felt after being diagnosed with an STI her ex-husband acquired in an extra-marital affair and subsequently
transmitted to her. Although her story clearly communicates negative emotions, Pamela is explicit that the situation was not as bad as it could have been. She recalls saying to her ex-husband: “It could not have been [an STI] that you gave me, it could have been worse, you know.” By “worse,” she means she could have gotten HIV. All of Pamela’s uses of passar are in reference to this situation; however, as previously documented, she does use contamin* to refer to HIV infection. Hence, it seems that contamin* is reserved for “worst case” scenarios. At least for her, passar does not rise to the level of severity of contamin*.

In addition to exhibiting wider applicability, passar also differs from contamin* because, whereas this latter term was used roughly equally by participants regardless of serostatus, the former was used almost twice as much by seropositive as seronegative individuals (19 speech events, compared to 11). One specific category largely accounts for the serostatus-related asymmetry in passar use: seropositive speakers’ greater use of the term in reference to themselves (7 speech events, compared to 1 for seronegative speakers). This finding is the result of two separate dynamics. First, it is the product of HIV-positive individuals demonstrating a marked preference for passar over contamin*. This is unsurprising, since, as noted in the case study of Xavier, passar is less medicalized and evokes less-negative connotations. The other dynamic seems to stem from passar’s directionality, that is, it encodes an action or object traveling from a sender to a recipient, and focuses on the sender. This semantic consideration makes it seem logical that seropositive speakers would have greater reason to use the term self-referentially than seronegative speakers. It also, however, suggests that we should find passar more heavily used by seronegative speakers when the reference is to one’s partner (i.e., “My partner could have passed/did not pass/avoided passing HIV to me”). That is not the case. Passar was applied to a partner just twice—once apiece by a participant of each serostatus.
Indeed, not only was *passar* not more heavily used by seronegative participants than seropositive, it was not even more heavily used overall in reference to partners than *contamin*.

Given *passar*’s “kinder” valence, this is highly unexpected and will be addressed in a subsequent section.

Table 6.3: Usage of *Passar*

<table>
<thead>
<tr>
<th>Passar</th>
<th># of Speech Events</th>
<th># of Speakers (Gender)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Refers to</td>
<td>Speaker SP</td>
</tr>
<tr>
<td>Self</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>Partner</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Others**</td>
<td>12</td>
<td>9</td>
</tr>
<tr>
<td><strong>Fictional/unknown</strong></td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td><strong>Known</strong></td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>19†</td>
<td>11</td>
</tr>
</tbody>
</table>

† Column does not tally vertically because one speaker or speech event contributed in more than one category.

One interesting commonality revealed by analysis of participants’ use of *contamin* and *passar* is that the terms are most likely to be applied in reference to “others” (not the speaker or his or her partner). If anything, this finding is stronger for *passar* than *contamin* (21/30 in comparison to 8/14 speech events, respectively). Within this subgroup of “others”-referencing utterances, it is again the case that most usages apply to “others” that the speaker did not know personally (15/30 total speech events). Although all uses of *passar* suggested disease
transmission was best avoided, varying associated emotional responses—either attributed to another person, or manifested on the part of the speaker—were found (discussed below). In general, there was a slight tendency for those using *passar* to be female rather than male. As in the preceding section, this discussion is organized by reference category, with subheadings of *Passar* in relations to Others, *Passar* in relation to partner, and *Passar* in relation to self.

*Passar in Relation to “Others”*

The most common use of *passar* was in reference to “others;” this occurred in 21 separate speech events. Such usage can be grouped into three subcategories: general statements on HIV (N = 6), statements about fictional or unknown people (N = 9), and statements made about people the speaker knew personally (N = 6). These subcategories also generally correspond to points along a continuum of associated emotional responses, ranging from a nearly emotionless statement of fact, to anger and fear.

The least emotionally charged instances of *passar* come from participants who used the term in making general statements on HIV transmission. The quote provided in the case study of Xavier (earlier in this chapter), in which he recommends “taking care not to pass [HIV] to other people,” falls into this category, but is perhaps the most emotionally engaged, since it is linked to notions of caring. More typical is Jorge’s statement, “Nowadays they have methods that—so that the mom doesn’t pass it, vertical transmission, ok?” or Rita’s: “Now, why is it that it’s faster for the man to pass [HIV] to the woman? Because of the semen.” These are usually statements of the participants’ knowledge about how HIV is transmitted, unconnected with any particular person or situation, and they come from seropositive and seronegative individuals (Jorge, Milene, Xavier, Rita, and Bibiana).
Other uses of *passar* occasion more emotion, even when the person “passing” HIV is fictional or not personally known to the speaker. As with *contamin* *, several participants used* *passar* in response to the vignettes. Commonly, this was in speculation as to how the seropositive character had become infected, or how s/he would react to the HIV diagnosis. Jorge, for example, claims it’s impossible to know how people will react. So, he predicts that the young woman who discovers her serostatus through routine prenatal testing may “run to [her partner’s] arms and cry and ask forgiveness, right? Or she could get there and say it was him that gave it to her.” The emotions recognized as possible in Jorge’s statement range from sadness and penance to accusation, with *passar* most associated with the latter, directed toward the fictional woman’s partner. Jorge’s partner, Iara, also used *passar* during her outpouring of scorn for the fictional truck driver, mentioned above, who she saw as wantonly engaging in unprotected sexual contact. She said, “He put her life at risk. Passing that virus.”

That a newly-diagnosed seropositive individual would be expected to direct reprobation or anger toward the person who “passed” HIV to him/her is assumed by Bibiana. In order to make a point about her own case, she invents a hypothetical situation, along the same lines as the vignettes included in the interview guide, about the emotional impact of contracting HIV from one of two sources: one’s husband or a casual sex partner. She claims that, while she thinks most women would be more revolted having been infected by their husbands, she does not see it that way. To Bibiana, it should be easier for a woman “whose husband had passed [HIV] to her” to forgive and “fight for the [continuation of the] couple” if she’d been married for years, had kids, and other ties to the relationship—none of which the fictional female (a stand-in for Bibiana herself) would have with a casual partner. Thus, even while she constructs an argument to explain her dissent from what she sees as a typical emotional reaction to infection, the fact that
her perspective is constructed as dissent serves to reify the connection between passar, betrayal and anger, and HIV. Overall, both seropositive and seronegative individuals (Jorge, Milene, Iara, and Bibiana) made statements that suggested increased emotional engagement when using passar in this hypothetical way, as compared to the abstract generalizations mentioned above.

More highly charged yet were instances in which participants used passar in reference to a real person, but not an individual with whom they were acquainted. In all four of these speech events, the speaker claims that discovery of positive HIV serostatus can provoke such rage that an individual will want to “pass” the infection to others. Bibiana’s disapproval of messages she saw on the Internet to this effect has already been discussed, but she returned to the theme at a later time, specifically to point out the threat such people pose to public health: “It could be an opportunist that’s there with the virus, wanting to pass it to you, and you don’t know.”

Iara told a similar story—with a twist. The individual in her narrative who was so angered by his HIV diagnosis that he attempted to infect as many others as possible was a young man she knew personally. However, Iara uses passar to report his past speech, which specifically references the unknown person who had infected him. She says that after becoming aware that he was engaging in unprotected sex with other female members of the religious group they both belonged to, she confronted him about his behavior. He dismissed her protests, saying, “I’m already fucked; some bitch gave it to me. Now what I want is for them to be fucked, too—they’re good for nothing.” Renato claimed that angry reactions like this were common, and that the story of an extreme case had been broadcast on the radio. Specifically, he told me of a report on the “Man of the Black Rose,” who, after being diagnosed with HIV, made a point of “going out with multiple women, in order to be passing” the virus. After achieving unprotected sexual
contact with them, the man would leave a black rose with a note that he had AIDS, and disappear.

All of these cases seem to perfectly encapsulate hegemonic notions of the way HIV-positive, unsanitary subjects may behave. Of course, such notions are as usefully interpreted as projections of societal fears as they are indications of seropositive individuals’ likely actions. Given the obvious rejection of such comportment—and, it may be inferred, their wish to distance themselves from it—on the part of all three speakers, it is worth asking why they did not use contamin* instead of passar to tell these stories. Bibiana, in fact, does use contamin* to give a more detailed description of the content of the online communication she witnessed. It may be that, since the particular sentence discussed in this section was constructed in such a way as to include HIV transmission to me, Shana (i.e., “wanting to pass it to you”), she chose passar to soften the message. Interpreting speech reported from third party, as Iara’s use of passar obliges us to do, can be tricky, for reasons previously explained. However, it’s important to note that the disapproval elicited by this story centers not on the unknown young woman responsible for infecting Iara’s acquaintance (the narrative offers no clue whether she was intentionally spreading HIV, or if she was even aware of her serostatus, after all), but on the young man and his brazen disregard for his vulnerable sexual partners. As such, whether what is reported is offered as verbatim or paraphrased speech, the non-use of contamin* may be seen as a way of withholding condemnation, given this incomplete background information.

Missing details and personal relationships, however, are not factors in Renato’s tellings of the legend of the Black Rose. Indeed, of the preceding narratives, it is this one that seems to most strongly demand use of contamin*. And yet, in both transcribed instances in which Renato recounts this story, he uses passar instead. It’s worth noting that neither Renato nor his partner,
Milene, ever used *contamin* in my presence; it may simply not be part of their lexicon in reference to HIV. On the other hand, Renato and Milene, like the couples in the legend, engage in unprotected sex. As such, the story may present too close a parallel for Renato to feel comfortable using such a stigmatizing term—and his desire to draw a clear distinction may explain why one aspect he emphasized about this story was essentially the lack of informed consent on the part of the female partners. He may see it as a key element that sets him apart from classically unsanitary subjects.

In the last group of utterances in which *passar* is applied to “others,” participants use it to talk about people they actually know. Two of these six speech events, Pamela’s account of transmission of another, unspecified STI, have already been discussed, but they fit into the trend of increasingly emotional reaction being noted here. As the above section makes clear, the newly infected individual can be expected to feel anger toward the transmitting entity. Pamela is no exception, claiming, “When I found out that it was him that had passed [it] to me, I slapped him in the face…” Iara, also expresses anger as she finishes a mental inventory of the few former partners she claims could have infected her (remember, she found out she was seropositive only after establishing in a new relationship and becoming quite ill), considering the risks each one posed to her. She settles on one, a man involved in the club scene who had multiple sex partners and used drugs. She concludes, “It was [him] that passed this bullshit virus…that bastard.” Although Iara’s tinderbox temper might lead one to expect her to manifest her displeasure publically, as Pamela did, maintaining a certain amount of secrecy about her serostatus is more important to her than any fleeting satisfaction she might derive from remonstrating a former lover.
Bibiana also uses *passar* to talk about a former lover, specifically, her ex-husband, and his worry over the possibility that he might have transmitted the virus to a new girlfriend. At the time Bibiana was diagnosed, her former partner’s serostatus was unknown. Luckily, according to her, his HIV results came back negative. But, because he could not immediately overcome his anxiety, he had delayed in getting tested. Therefore, there was a period of time during which “He was desperate because he didn’t know if he’d passed the illness to [his new partner]”. In other references to this episode, Bibiana also uses words like “worry” and “suffering” to describe her ex-husband’s state of mind. Though she mocks the metaphorical paralysis his fear of being diagnosed with HIV causes (i.e., he is unable to simply go get tested), there is never any hint of moral judgment about how this delay may increase his new partner’s HIV exposure. An important influence on her portrayal of his behavior is the evident fondness she still has for him; such feelings are likely to prevent her from using *contamin* *, which would tag him as an unsanitary subject. In this case, our sympathetic attention is directed to the fear and desperation he experiences.

Milene, Renato’s seronegative partner, also links *passar* to fear when discussing “others,” but the fear is her own. It relates to her young son and the older, seropositive neighbor boy with whom he often plays. Both children are quite accident-prone, and she says, particularly in the summer, “I’m afraid of [the neighbor boy] passing [it] at some point that they both get hurt, you know?” The use of *passar*, as opposed to *contamin* *, makes sense in light of the framework being outlined here, for several reasons. First, the potential source of infection in this segment is a child who was infected perinatally—hence, he is not “to blame” for his serostatus. In addition, the couple had a caring relationship with the boy. His wellbeing came up during multiple interviews; at one point during the research he was hospitalized with pneumonia, which Renato
and Milene claimed was because his family was not strict enough with him about taking his ARVs. Renato even positioned himself as the child’s teacher in the regard, essentially instructing him in the discipline of sanitary citizenship. Thus, when Milene emphasizes, “That’s the only thing I’m afraid of. But I don’t exclude him because of that, ok?” her assertion rings true. By admitting her fear, she also admits that she sees the boy as representing a risk for her son, but her quasi-parental relationship precludes punitively marking him as such.

From the uses of passar considered thus far, it is evident that although “passing” an HIV infection is not considered a positive action or event, it need not be interpreted as so inherently stigmatizing, or, indeed, criminalizing, as when rendered using contamin*. In essence, by choosing a different word to portray the act, speakers change the meaning of the act itself. This can be seen when general knowledge about HIV transmission is discussed by participants with impartiality or even indifference. On the other hand, when the talk turns to potential infection of people with whom the speaker has a closer relationship, the emotional overtones strengthen. In the cases documented here, that emotion can be anger or fear. However, once the possibility of infection becomes a serological fact, anger takes over as the predominant emotion.

**Passar in Relation to Partner**

As noted above, there are strikingly few applications of passar to one’s partner. This construction is used by only Adriano and Iara, and in both cases, it is to denote possible transmission that did not take place. Adriano, for his part, mentions another possible explanation for his continued seronegativity when he says, “maybe what [Rita] has is incubated and [she] doesn’t pass it to anyone.” Iara talks about she and Jorge’s differing perspectives on which one of them brought the virus into their relationship: “So he thought that he could have passed it to me. I never thought that....I always thought I could have passed it to him.” Although the
intriguing paucity of utterances that fall into this category deserves more attention, the subject will be taken up in the section on *pegar*. At present, it is sufficient to note that neither case is associated with particularly emotive language, the statements being more along the lines of laying out the facts. In this sense, they differ markedly from the uses of *contamin* as it referred to partners—this is not speech that shames, alienates or is designed to frighten.

**Passar in Relation to Self**

Perhaps because they also denote transmission that did not actually occur, two of the seven self-referential uses of *passar* have a similar matter-of-fact quality. This characterizes the only use of the term by a seronegative participant. Juliana, who only rarely externalizes her emotions anyway, explains that her professed inability to use condoms makes mutual testing for HIV and other diseases of paramount importance: “That’s my opinion, because whatever I have, I don’t want to pass it to anyone.” Likewise, Bibiana projects only a slight measure of regret when asked to imagine if her relationship with Felipe would be different, had he tested positive for HIV. She says, “Well, I would feel guiltier, right?...Because if he had it, it would have been me that passed it to him.” Given that both women find themselves in situations that, for different reasons, virtually preclude any of this “passing,” it is perhaps unsurprising that they do not invest much emotion in these comments.

But the near impossibility of transmission does not leave Iara similarly glib. In answering questions about her continued—and previously atypical—lack of sexual desire, she is clearly unhappy at the thought of not fulfilling what she calls Jorge’s “sexual needs.” She recalls friends’ advice: to stop being such a drama queen⁹¹—as well as their implicit threat: there are

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⁹¹ This is a difficult translation. It comes from estar se fazendo, literally, “to be making oneself.” This phrase is usually followed by a noun or adjective (de vitima, or dificil), and means something like “play acting” (i.e., the victim, or hard-to-get). In this case, Iara uses the phrase in reference to herself and it stands alone, appearing to convey that she is not making a big deal out of nothing.
lots of women out there looking for a man like Jorge. She claims, however, that “As much as I try to change my way of thinking and things… There are days that I don’t like him to get close to me. It’s not just nonsense, you know? I think like this, if it were to happen that I pass certain things… It’s not...It’s not nonsense. There’s no way.” Iara’s dejection as she spoke was palpable, and seemed even to blunt the normally precise and colorful articulation of her feelings. When she mentions “pass[ing] certain things,” it is unclear whether she means passar in the sense of “going through an experience” or of transmitting infection, as is our interest here. Similarly, when she says, “There’s no way,” she could be repeating the impossibility of changing how she feels, or she could be referencing the unlikelihood of transmitting HIV to Jorge, given the lack of unprotected sexual contact between them. As she continues to talk, she seems to pull on all of these meanings to craft a narrative filled with uncertainty and a hint of despondency about the future.

The remaining uses of passar to refer to one’s own role in the possible transmission of HIV are decidedly less ambiguous, but even more explicitly linked to fear. Renato and Rita, two seropositive members of couples that never or only inconsistently use condoms, both say they fear passing the virus. For Rita, this fear was so overwhelming when she was first diagnosed that it led her to create what she called her mundinho, or “little world,” in which she isolated herself from everyone except members of her immediate family. She explained, “I was afraid of passing [it] to someone…I didn’t want to pass that to anyone, you know?” As mentioned above, she stated the possible seroconversion of her partner, Adriano, as one of her greatest worries.

Renato never cited anxiety over Milene’s potential infection as his greatest source of stress, but he did claim to be afraid of this eventuality, and speculated he might even need psychological help should it occur. He acknowledges the couple’s non-use of condoms and then
continues: "I'm the one that's wrong [for not using condoms], but I am afraid of passing it to her.” And later he asserts, “Even today, I’m scared to death” [about it]. Why, then, persist with a behavior that leads to such fear? Aside from Milene’s contention that Renato cannot maintain an erection when using a condom, and Renato’s interpretation of Milene’s acceptance of the couple’s sexual practice as “the greatest proof of her love,” another justification is offered, which echoes what Adriano said about Rita’s “incubated” infection. Renato says that because his viral count is so low, “I think I don’t pass it to her.” Interestingly, then, for Renato (and Adriano), lack of condom use—a behavior which violates biomedical recommendations for seropositive individuals, and can be seen as emblematic of unsanitary subject status—is partially justified by recourse to the very serological measurements biomedicine uses to define “health” for those infected with HIV. In that case, it’s little wonder that Renato chooses to resignify such actions by using passar instead of contamin*. That his own linguistic construction does not entirely convince him, however, comes through in the multiple linkages we find in his discourse between passar and fear.

To briefly summarize this section, passar was employed more frequently in this body of data than contamin*. It was also applied to STIs generally (rather than solely HIV), and with a wider attendant range of emotion. In fact, the use of passar, both through comparison of its deployment in various reference categories, and as compared to contamin*, demonstrates that the meaning of HIV infection, and the emotional reaction associated with seroconversion, is not static, but contingent on multiple factors. Nonetheless, the majority of utterances still involve “Others,” which may be partially explained by passar’s “directionality.” That is, passar, as it relates to HIV infection, clearly focuses attention on the sender or origin. Because of this property, it is unsurprising that seronegative speakers were particularly reticent about applying
the term to their seropositive partners; this would call attention to precisely the serological reality that accords least well with notions of couplehood (i.e., it constructs the partner as a source of contagion and harm). In addition, despite the relative flexibility noted above, there is a generally negative operant understanding of HIV among the speakers—voiced especially plainly in relation to “Others”—in that those who discover they have seroconverted are expected to feel anger, and those who sense the possibility of transmission frequently report fearful reactions. In some of the examples considered above, the avoidance of passar, in favor of the next term to be analyzed, pegar, turns out to be of paramount importance for the semantic quarantine.

Words in Focus: Pegar

Whereas passar was used more frequently, more flexibly, and by more speakers than contamin*, pegar is used still more frequently, even more flexibly, and by more speakers than passar. Of any term used to denote HIV transmission, pegar was by far the most commonly employed, appearing in 87 speech events throughout this corpus of texts. Like passar, in Portuguese pegar has multiple meanings, thus it can require one of several different translations to English. Pegar can be used extremely colloquially as a filler, translating to something along the lines of “I went and told him that…” where “went” does not actually denote going anywhere, but serves merely to emphasize the action communicated by the other verb in the sentence (in this case, “told”). Pegar can also mean “to stick (to something else),” “to grab or catch a physical object,” or “to catch” metaphorically, in the sense of discovering someone doing something (whether good or bad), or contracting an infection or illness. Only this last meaning was counted among the 87 speech events mentioned above.

Again, like passar, and in contrast to contamin*, pegar in this latter sense did not refer exclusively to HIV. Other illnesses that participants used pegar to talk about included cold/flu,
cancer, diabetes, STIs, Hepatitis, and opportunistic infections. In fact, for two categories of use, non-HIV references were more frequent than HIV-related uses: seropositive speakers were discussing HIV only one out of the four times they used *pegar* about themselves, and in neither of the two times seronegative speakers used *pegar* with reference to their partners was HIV the topic of their statement. Since *pegar* is such a common word (throughout the texts and in Portuguese in general), based on available data, no conscious motivation can be reliably attributed to speakers’ application of the term to infections other than HIV in any particular case. And yet, lack of evidence for conscious motivation does not equate to meaningless use. In this vein, it is notable that those who suffer from tuberculosis or cancer, for example, are not held culpable for their illnesses the same way HIV-positive individuals tend to be. By using the same linguistic structure to reference both HIV and other, less stigmatizing infections/illnesses, the speakers create a sort of discursive equivalence. This may, in turn, suggest a more fundamental similarity, by virtue of which HIV could lose its peculiar blame-worthiness.

Every participant in this study contributed at least one utterance containing *pegar*. Seropositive and seronegative speakers were involved in roughly equal numbers of speech events overall (43 and 41, respectively), and when using *pegar* to refer to “others” (32 and 29 speech events, respectively), but their use differed markedly when referring to either themselves or their partner. Seronegative speakers used *pegar* self-referentially in more than three times as many speech events as seropositive speakers did (14 vs. 4 uses), an effect that becomes even stronger if one compares only those statements dealing with HIV (11 vs. 1). On the other hand, seropositive speakers were much more likely to use *pegar* to refer to their partner than seronegative speakers were, doing so during eight speech events—all of which dealt specifically with HIV. As noted in
the previous paragraph, although seronegative speakers used *pegar* twice to talk about their partners and infection, that infection was never HIV.

These patterns of use can be partly explained by the way *pegar* serves, as a component of the semantic quarantine, to attribute agency regarding HIV transmission. Although the specifics of this usage will be explored shortly, two characteristics deserve mention now, since they guide the analysis of examples. First, as stated in the case study of Xavier, *pegar*, in the sense that concerns this research, is most adequately translated as “to get.” As in English, this “getting” can be the result of determined effort, or it can be incidental, even accidental. Thus, use of *pegar* leaves open a range of possible actions that may have led to someone “getting HIV.” These, in turn, correlate with varying degrees to which the infected person may be seen as “responsible” or “to blame” for his or her serostatus. On this continuum of responsibility, vertically infected infants represent the blameless end of the spectrum; adults infected through “promiscuous” or “unnatural” sexual behavior or drug use represent the opposite, “got what they asked for” end, and other cases fall somewhere in between. This means that, unless the speaker chooses to specify, *pegar*—unlike *contamin*—is not automatically associated with blame or responsibility for serostatus.

Questions of moral responsibility aside, however, the second consideration to which we must attend involves linguistic attributions of agency. Grammatically, whereas the verbs *passar* and (sometimes) *contaminar* emphasize the sender or source of infection, *pegar* makes the action or condition of the newly/potentially-infected person the focus of the sentence. We might call this the “agentic property” of *pegar*. As such, the message conveyed by the phrase, “She got HIV from him” is clearly and significantly different than “He passed/gave HIV to her,” even if the serological reality communicated in both sentences is the same. It’s even possible, with
pegar, to background the source of infection to the point that it disappears from the sentence altogether, as would happen if the “from him” were omitted in the former example sentence.⁹² Such constructions imply that the source of infection is a non-issue.

These two characteristics of pegar—the ambiguity it allows in terms of responsibility for becoming infected, and its ability to downplay the source of infection—make it an important discursive resource for HIV-serodiscordant couples as they work to construct a reality in which their relationship is read not as mortal risk, but as “normal.” As the soon-to-be-analyzed examples demonstrate, pegar allows linguistic agency for HIV exposure and/or potential seroconversion to be attributed to the seronegative partner while withholding any suggestion of moral responsibility. The benefit to the couple is that both partners escape being marked as unsanitary subjects, and the seropositive partner is not constructed as a source of pollution. Since pollution is, by definition, “that which is out of place,” (Douglas 1966) this avoids introducing tensions into the relationship that may tear it apart.

On the other hand, that it is possible to use pegar in conjunction with the attribution of responsibility for infection is also evident from participants’ utterances. This, however, only appears in their use of pegar in relation to “others,” which constitutes by far the greatest share of overall use of the term (61/87 speech events). Indeed, the fact that, for all terms considered in this analysis, speech events concerning “others” and HIV transmission were much more numerous than those referring to the speaker or his/her partner may reflect a relationship-specific restriction on what is “sayable” (Goldstein 1992) that itself functions as part of the semantic quarantine. By beginning the analysis with references to “others,” the contrast between the way

⁹² It’s possible to do the same thing in the latter example sentence as well (i.e., “He passed HIV”), but it is a much less commonly heard construction, and passar always retains an implicit idea of passing something to an entity.
participants could talk, and the way they choose to talk about their own relationship can be more fully appreciated.

Table 6.4: Usage of Pegar

<table>
<thead>
<tr>
<th>Pegar</th>
<th># of Speech Events</th>
<th># of Speakers (Gender)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Speaker SP [Non-HIV]</td>
<td>Speaker SN [Non-HIV]</td>
</tr>
<tr>
<td>**Fictional /unknown</td>
<td>13 [1]</td>
<td>8</td>
</tr>
<tr>
<td>**Known</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>43†</td>
<td>41†</td>
</tr>
</tbody>
</table>

† Column does not tally because one speaker or speech event contributed in more than one category

**Pegar in Relation to “Others”**

As with passar, the uses of pegar in relation to “others” can be grouped into three broad categories: uses that reference transmission of infection at its most general or abstract, those that refer to hypothetical cases or real individuals with whom the speaker is not acquainted, and those that refer to people the speaker knows. In each of these categories, women were at least slightly more likely to contribute speech events than men, although, as mentioned above, all participants used the term at least once.
General or abstract statements were the most frequent type of this use overall, constituting 23 of the 61 applications of pegar to “others.” Seropositive and seronegative speakers made roughly equal contributions (11 and 12, respectively), although more seropositive than seronegative speakers used pegar to talk about transmission of infections other than HIV (3 of 11 vs. 1 of 12). All six women contributed utterances in this category, while only half of the men did.

Five of these references are purely descriptive, as was the case with similar uses of passar. Jorge, for example, in recounting his pre-HIV test counseling experience, describes the content of the session by saying it covers, “How [you] get [HIV], how [you] don’t get it, they ask you questions.” Wílian closely echoes this kind of usage as he describes his knowledge about HIV prior to his diagnosis. He says he knew “nothing about this. Not what [HIV] was, or what it wasn’t, how [you] get it, how [you] don’t get it…” Milene and Iara also talk very matter-of-factly about HIV transmission, saying respectively, “it was the homosexuals that got it first,” and “The majority of men are like that. They get [HIV] and they don’t even know who from.” Rita uses pegar to talk about preventing transmission during pregnancy. We would translate her comment into English as, There are ways “for the baby not to get [HIV].”

Linguistically, Milene and Iara’s uses differ from the others because they specify an actor who does the “getting” (“homosexuals” and “men”). Jorge and Wilian do not do this, which opens the possibility of translating their uses differently. When Jorge, for example, says the counselors review “Como pega, como não pega,” the most idiomatic rendering of his statement is “How [you] get [HIV], how [you] don’t get it,” as given above. However, an alternative translation that taps into the “to stick” meaning of pegar is also possible: counselors talk about “How [HIV] sticks, how it doesn’t stick…” By using this construction, both men minimize the
agency of infected people—after all, it is HIV that “sticks” or doesn’t. Rita’s usage goes even further in exempting certain individuals from any responsibility for their infection. She says literally, “Pra não pegar no nenêm,” or there are ways “for [HIV] not to stick to/on the baby.” In this phrasing the baby is not an active agent, but rather a target for the virus, while the mother’s role in potentially passing HIV to her child is totally obscured. All of these examples are devoid of any attribution of responsibility for infection, a linguistic aim facilitated by using *pegar*.

Another group of utterances deals specifically with the mechanics of HIV transmission, and the ignorance or prejudice manifested by people who hold false beliefs about “getting” the virus. Four participants spontaneously mention this—even citing very similar misconceptions about how HIV can be transmitted. Pamela, for example, says, “It’s that people are prejudiced, you know, Shana. They think that if you talk to the person, if you take their hand, you’re going to get the disease. If you give a hug, you’re going to get the disease.” Juliana offers, “I never heard that you can get HIV by sharing a cup of water, or *chimarrão*…or a piece of candy. That’s where the person starts to be willfully ignorant...And me, well, I stop [interacting with them] right there.” Jorge and Rita also lament the common belief that sharing towels and dishes is risky.

But even when these participants are setting the record straight about how HIV is transmitted, there is no suggestion that a person engaging in those acts is or should be seen as responsible, or blamed for transmission. As Rita notes, if she had to explain HIV to someone, she would “explain that AIDS—you get it from sexual relations, in oral sex, anal sex…Syringes, if you share them with other people, [you can] get it. Umm...blood transfusions, [you can] get it.” The remarkable characteristic of this segment is that oral and anal sex, drug use, and
blood transfusions are all treated as equivalent routes of exposure—that is, as though becoming infected via a blood transfusion would mean the same thing as becoming infected through drug use. This, as previously analyzed speech events have demonstrated, is simply not the case, in terms of stigma and consequences for a seropositive individual’s identity. Yet _pegar_ allows Rita to gloss over these differences, and—like the other segments quoted here—focus on the general public’s judgmental, ignorant perception of HIV, instead of the (potentially “blameworthy”) actions of those who acquire the virus.

There are various other ways that participants use _pegar_ to contest hegemonic interpretations of HIV. All, however, subvert associations of blame with seropositive people. Some of these (seven speech events, from Bibiana, Rita, Adriano, and Juliana) simply contradict what the speakers take to be widely believed ideas, while others (three speech events, from Iara, Rita, and Milene) juxtapose other infections or illnesses to HIV. The ease of contracting tuberculosis, for example, in comparison to HIV was mentioned by both Iara and Milene. The latter noted: “Someone sneezes close to you and you get it…I mean, you can run your hand over something, touch your hand to your face or rub your nose, and you get it!” But if some speakers emphasize the relative difficulty of contracting HIV, not all participants agreed. Juliana, for example, asserts that, “[HIV] is a disease that, nowadays, it’s not difficult to get.” Bibiana expressed her confusion about the dynamics of seroconversion: “This business of the person already having an immunity and not getting [HIV]….Why does the woman not get it? What resistance does she have that she doesn’t get it?”

Bibiana was not the only participant who, after comparing her understanding of the likelihood of transmission with her own observations, didn’t see a perfect fit. When I asked Adriano if he felt particular sexual practices posed more risk of infection than others, he simply
stated, “I’m starting to come to the conclusion that (slowly, thinking) sexual contact, with no protection, doesn’t make you get it so fast.” But later in the same interview he seemed to suggest that the chances of infection from any particular exposure were unpredictable, almost unfathomable. After patiently listening to me attempt to explain oral sex harm reduction techniques, Adriano admitted he didn’t think they would be very useful, since “It can turn out that you don’t get [HIV] because you don’t ingest a large quantity of [semen]. But at the same time, you can [seroconvert], even if it’s just a drop.”

Of course, these speakers have different motivations for portraying HIV in particular ways. Bibiana repeatedly returned to the HIV-positive women she met in the clinic who, despite unprotected sexual contacts, had not passed the virus to their male partners. She at times seemed to feel cheated that she had seroconverted when so many other partners did not. Adriano, on the other hand, was one of those partners, and he did not wish to modify his sexual practice. Therefore, for him, it is convenient to claim both that sexual routes of exposure don’t seem very efficient as modes of transmission, and that every sexual exposure carries a potentially equal and, in any event, incalculable risk. Were that the case, there truly would be few persuasive reasons to change his behavior.

Even within a couple, differences in serostatus can provoke different responses to the same question. Both Rita and Adriano, for example, were asked whether “some people have more risk of getting HIV than others.” Rita objected: No, “because getting the disease isn’t exactly like that, ok?” By this she meant that the kinds of people one might “expect” to be seropositive (i.e., stigmatized groups) are not the only ones with the infection. She went on to emphasize the importance of being educated about which behaviors are likely to allow transmission of the virus. Her partner, Adriano, when asked the same question, however, skips
right over behavior, and focuses on immunological competence, which he claims varies from person to person. Unlike Rita, he answers the question in the affirmative, elaborating that some people “have pretty low immunity and they’re much more likely to get [HIV] quickly.”

The difference in this couple’s answers comes down to the particular identities from which, differentially positioned by serostatus, they are trying to distance themselves. For Rita, already seropositive, it is important not to be subsumed in the stigmatized subpopulations historically seen as “risk groups” for HIV. Hence, she focuses on the mechanics of transmission—that is, behavior—and the way practices, not social identities, are what leave an individual vulnerable to infection. Adriano, on the other hand, remains uninfected despite multiple (consciously accepted, if not quite “deliberate”) exposures. For him, emphasizing the role of behavior in HIV transmission would highlight actions he’s taken that might well warrant his classification as an unsanitary subject. He avoids this undesirable outcome by claiming that any individual’s likelihood of seroconversion depends essentially on immunological factors—an internal state about which he notes the person in question may not even be conscious.

Thus, Adriano creates a context in which purposeful behavior is of only marginal relevance to seroconversion and, by extension, to identities connected to seroconversion. To be more explicit: if certain individuals can undertake behaviors associated with unsanitary subjecthood with little risk of infection, then the justification for such classification appears to be refuted. Adriano’s immunological strength (evidenced by his continued seronegativity despite exposure to the virus) serves to bolster another kind of immunity—in this case from the discursive contagion of being named an unsanitary subject. What bears accentuating here is that, despite giving contradictory answers to my question, Rita and Adriano both (are able to) use *pegar* to address transmission risk while backgrounding notions of blame for serostatus.
*Pegar* was also used to elide suggestions of responsibility while contesting the once-hegemonic (and still pervasive) idea that HIV is a death sentence. Rita, for example, muses, “I saw that with [HIV], I have a lot of time to live. More than with cancer, because when you get cancer [that’s it], you know?” In terms of impact on one’s future, she seems to say that HIV is not that bad. Bibiana agrees, saying, “But even in old age, if you get [HIV] at age 50 and take the medicine, you’ll last into your 70s.” In both examples, *pegar* is used the same way, although to refer to “getting” different infections/diseases. In neither case is there any intimation that the affected party is to blame for the situation.

Indeed, such an attribution is difficult to find with reference to any of the segments analyzed in this section. Even more remarkable is the lack of linguistic reinforcement (within the same sentence) that getting HIV is undesirable, although society’s prejudice against seropositive people is made clear. Rita’s statement above even states that, in terms of survival time, getting HIV is preferable to getting cancer. I am not, of course, suggesting these usages should be understood to mean that HIV infection is a positive event. All participants bring negative associations regarding HIV to these encounters from other contexts (what Gee 2005:7 calls “capital D ‘Discourses’”); thus, the virus is still clearly to be avoided. Overall, however, general or abstract statements about HIV are characterized by a matter-of-fact quality and absence of attribution of blame for seroconversion. This begins to recede when other types of utterances are analyzed. Transmission comes to be increasingly associated with objectionable behaviors when *pegar* is applied to hypothetical or unknown “others.”

All but one of the utterances in the category of hypothetical or unknown “others” were from female participants, and two-thirds (14/21) of these uses of *pegar* occurred in the context of talking about hypothetical situations, whether in response to the vignettes in the interview guide, "93 Translator’s note: Yes, she really used “old age” to refer to age 50!"
or those invented by participants themselves. In terms of the other uses, that is, speech events that applied *pegar* to real people whom the speaker did not personally know, Bibiana contributed four of the six segments. Two of these, detailing online communication regarding how a seropositive individual might infect his or her partner, have been described in a previous section. The remaining two introduce the topic of other female clinic patients and their seronegative partners. Bibiana’s tone falls somewhere between wonder and complaint as she exclaims, for example, “And they have the disease and their husband doesn’t, and they keep having sex and the husband doesn’t get it, Shana!” Iara looks simply incredulous when I describe a similar situation to her, asking, “And [the male partners] don’t get it?” Pamela and Milene also mention other women at the clinic, but the storyline is not a happy one. Pamela says, “I heard a woman saying that she’d gotten HIV from her ex-husband, that he got it and never told her.” Milene tells a similar story, about a woman “that was married for twenty years. She got it from her husband.” The agentive property of *pegar* is evident in each of these cases—that is, regardless of possible variation in the motivation and behavior of the seropositive individual involved, the seronegative partner is placed in the active role, in terms of attributing linguistic agency (although not blame). In serodiscordant interactions, the seronegative individual is the entity that “gets” (or doesn’t) HIV.

This is also the case with each of the uses that refer to fictitious characters. Three seropositive and three seronegative participants (Rita, Bibiana, Iara, Pamela, Juliana, and Adriano) made use of *pegar* in this way. The interesting variation that occurs among these utterances, however, has to do with assignations of blame or moral responsibility for contracting the virus. Certain hypothetical scenarios were more likely to elicit such statements than others,
and in all cases these attributions hinged upon the protagonist having engaged in morally suspect behavior.

As such, it is unsurprising that the vignette featuring Maria, the character diagnosed with HIV as a result of routine pre-natal testing (for full text of vignette, please see Appendix II), did not provoke these denunciations. No information about her sexual history was provided, other than that she had met her partner of one year at a family member’s birthday party. Some participants, by dint of personal experience, clearly identified with Maria. Pamela, for example, sympathized with how it would feel, “to discover that you got a sexually transmitted disease, you know, and you hadn’t done anything [wrong], and then discover that your husband got AIDS.”

As noted in the section on *passar*, Pamela recounted a similar experience, contracting an STI from her unfaithful ex-husband. Perhaps for this reason, she not only assumes that Maria was infected by her current partner (and not vice versa), but also that the protagonist had not done anything else that might have exposed her to the virus. Maria (like Pamela herself) is above reproach.

Rita and Juliana likewise do not assign Maria any blame for her serostatus, although they refrain from assumptions regarding the source of the infection. Rita points out that the vignette does not include information about the serostatus of Maria’s partner. She concludes, “So there’s that doubt: who is it that had [HIV], was it her or him? How did she or he get it? Neither knows.” For Juliana, the source of the infection seems scarcely to matter. In response to a question as to how the hypothetical situation could have come about, she says, “[Maria] must have been with someone who had it, and gotten it without knowing.”

Participants who invented their own hypothetical situations in the course of interviews also tended to dispense with fault-finding when using *pegar*. Bibiana’s story about a fictional
woman, married for years, who had gotten HIV from her husband, was recounted in the section on *passar*. In the story, she uses both *passar*, when she needs to specify that the husband is the source of the infection, and *pegar*, which nonetheless also puts the wife in an active role. The net effect is to point a finger at the husband, but resist any suggestion of an unforgiveable trespass (she tells this story, after all, to argue for her greater willingness to forgive the husband). She remains matter-of-fact as she places herself into another example of this type, saying, “Like, [if] ‘I met a guy yesterday, had sex with him and got the virus,’ ok?” Adriano adopts a similar tone when discussing what happens when a man loses his wife and family, after his extra-marital affairs are exposed (Adriano claims such affairs are to be expected from the vast majority of men). The man in question will have many sexual partners, which causes him to “get a disease here, get a disease there, get one from somewhere else, and it starts to spread; that’s the worst of all.” Although he ends this speech event with a negative judgment, that judgment seems to represent rueful tsk-tsking more than any explicit statement of blame for choices that could have been made differently.

Adriano does attribute responsibility for serostatus to one of the protagonists in the vignettes, however. Marcela, who left her parents’ home to pursue a relationship with a trucker, and later turned to commercial sex work to support herself (for full text of vignette, see Appendix II) is not seen as a victim of circumstance, but as fully in control of her exposure to the virus. When asked how Marcela had become infected, he answered, “Ah, how did she get it? Well no one does anything they don’t want to do, understand? Especially if she got it working in that unmentionable place….she got it working in a ‘night club’.” It bears stating that the

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94 In this case, my question did contain *pegar*, which may have influenced Adriano’s word choice in response.
95 Translator’s note: A “night club” in the spoken Portuguese of Porto Alegre is sometimes a bar with live music, sometimes an undercover brothel.
vignette does not specify how Marcela became infected; there are various possibilities and Adriano draws his own conclusion. It should also be noted that this is the only response from a seronegative individual that uses *pegar* in conjunction with assigning moral responsibility for HIV transmission.

This same vignette gets a different reaction from Iara, however. Some segments of her response have already been explored, including her unhesitating identification of the trucker as the source of Marcela’s infection. She fumed: “She got it from the trucker, that bastard. And he knew.” Again, this is an assumption on Iara’s part. Nothing in the vignette provides justification for saying definitively how Marcela was exposed to HIV—and this is precisely the point: participants construct their own realities within the confines of the story. Thus, Adriano focuses on Marcela’s involvement in sex work rather than potential HIV exposure in the context of the earlier relationship. For Iara, the lack of care the trucker exhibited by not informing Marcela of his serostatus comes in for denigration; sex work is rendered irrelevant.

The personal circumstances of each respondent may explain this divergence. Adriano, as a seronegative individual who engages in unprotected sex with his partner, may be inclined toward hypothetical explanations that will not lead to parallel suggestions for real behavior change on his part. Remember, he has already portrayed exposure to HIV through sexual contact as inefficient in terms of transmission (having said that sex, “with no protection, doesn’t make you get [HIV] so fast.”). Therefore, if Marcela got HIV through sex, it can’t have been through the kind of sex Adriano has, but sex that is somehow different: commercial sex.

As for Iara, having been unwittingly infected by a former sexual partner, and still harboring anger and bitterness over this fact, she may wish to draw attention to the actions of the trucker, which she interprets as nefarious and condemns. This is not to say that Iara lets Marcela
off scot-free. Iara claims that, in light of the HIV diagnosis, the fictional protagonist should discontinue commercial sex work because, “She’s risking getting something else from other people, other diseases. Even if she’s always careful and does her treatment.” In this construction, commercial sex work appears to entail lack of condom use (or at least lack of effective condom use), and Iara implies that if Marcela continues in the profession, she’ll be responsible for whatever other diseases come to afflict her. The underlying message seems to be that, post-diagnosis, Marcela must make responsible decisions about her sexual behavior, as Iara has done in her own life. These responses, then, are most interesting for what they reveal about each participant, and what HIV transmission means to him or her. Returning to the primary argument being made here, however, it is particularly relevant that, although Adriano and Iara attribute Marcela’s infection to different sources, they both clearly assign disapproval or blame for her seroconversion based on what they choose to single out as socially unacceptable actions.

The last vignette, about a once-married man named Roberto, also provoked disagreement among participants about routes of exposure and attributions of blame. After discovering his wife’s affair with his best friend, Roberto becomes depressed and begins drinking to excess in bars (for full text of vignette, please see Appendix II). In relation to this case, Adriano, in contrast to his response to the vignette about Marcela, completely refrains from prediction. When asked to explain the route of infection, he merely notes, “It’s anybody’s guess how he got it. You can’t tell why, or how, or where.” Thus, Adriano does not highlight transgressive behavior on the part of the protagonist, and avoids dealing with blame and conjecture about transmission. Iara and Bibiana, however, were not so circumspect. When asked about mode of transmission, Bibiana laughs: “He got it during his drinking binges…he asked for it, you know?” Iara laughingly gives two possibilities: “He got it from his wife, or…he took it up the butt [when
he was out drinking at night.” Both women clearly hold Roberto responsible for his serostatus, whether as a result of general drunkenness, or specifically because that inebriation facilitated homosexual contact between men.

Taking up the reference (sub) category of “known others,” given the tendency for speakers to minimize, whenever possible, the likelihood of someone they care about being marked as an unsanitary subject, it is to be expected that they would use *pegar* more frequently than *passar* or *contamin* when discussing those individuals’ involvement in HIV transmission. This is indeed the case, with *pegar* registering 15 such speech events, as compared to 6 for *passar* and only 2 for *contamin*. In more than three-quarters of these cases, speakers using *pegar* took advantage of the ability to leave questions of culpability unaddressed, preferring to emphasize the fear their family and friends experienced in conjunction with exposure to HIV.

One situation, however, did elicit explicit attributions of responsibility for contracting the virus. As in the previous section, this correlated with the seropositive person having engaged in behavior seen as immoral.

The three speech events in question revolve around the exposure of Juliana’s daughter to HIV, which was mentioned in the case study in the first half of this chapter. To refresh the reader’s memory: as Juliana recounts the story, her daughter’s husband “had an affair, got HIV, and hid it” until the onset of symptoms made this impossible. This resulted in an extended period of exposure for Juliana’s daughter, but, as Xavier happily reported, “She has blood just like her mom’s; she doesn’t get [HIV].” As noted previously, then, *pegar* is used in service of communicating the blamelessness of Juliana’s daughter, in terms of her exposure to the virus.

However, Juliana also uses *pegar* multiple times to emphasize her former son-in-law’s responsibility for his infection. She reports telling her daughter, for example, “When you
married him, he didn’t have [HIV]. You married him when he was normal, healthy. He got it because he cheated; he did something he shouldn’t have. He knew who he was running around with, knew that [the other woman] had it. It happened because he wanted it.”

There is no hint of pity in this unyielding assignation of blame. In fact, Juliana goes further, discursively, than any of the other pegar statements analyzed here. Her former son-in-law is not merely “responsible” for his infection. It’s not simply that he “deserved” to be infected, given his behavior. Juliana portrays him as actually “wanting” to be infected. Though her statement is not meant to be taken literally (i.e., her son-in-law did not actively pursue the opportunity to seroconvert), it is a measure of the severity of his moral infractions. He not only committed adultery, he also engaged in years of deceit, putting the life of the mother of his children at risk. It should be acknowledged that, in general, female participants tended to reprove the former infraction more strongly than male participants did. But even Xavier, who admitted that his own fidelity to past partners had been less than perfect, could not excuse lying about one’s HIV status, or the callous way it was finally revealed (over the telephone). This double offense sealed the son-in-law’s discursive fate: guilty.

We might wonder why, in that case, more value-laden terms—like contamin*, for example—were not used in place of pegar. Since the couple eventually divorced, there seems little reason to save the former son-in-law from classification as an unsanitary subject. One contributing factor may be that Juliana’s daughter escaped the mortal harm of seroconversion. Had she contracted HIV, the offense would have been of a different magnitude—both discursively and in criminal terms. Juliana notes that, “if [her daughter] had gotten it, she would have brought a court case against him.” Under such circumstances contamin* might well have been invoked.
Multiple, continuing relationships also complicate the situation. Although he is now Juliana’s daughter’s ex-husband, the man remains involved in the lives of their children, and, hence, the rest of the family’s lives as well. In addition, prior to his marriage to Juliana’s daughter, the man was friends with Xavier—and still comes to visit, even seeking advice from Xavier and Juliana about his life. It is in this capacity that Juliana discovered that her ex-son-in-law had not revealed his serostatus to his new partner. She reports scolding him: “I said, ‘You have to come clean, man. You know, she can sue you if she gets [HIV]. Because you’re deceiving a person, if that person doesn’t know.’” Thus, by virtue of continuing bonds of family and friendship, he avoids the discursive exile that contamin* would effect. On the other hand, unwilling or unable to make different choices, he has not redeemed himself and therefore still carries the blame for his past actions.

Absent such infractions, however, other applications of pegar to those with whom the speaker has a personal relationship largely refrain from assigning blame for HIV transmission. Instead, they typically focus on the fear and anxiety exposure to the virus produces. A couple of examples suffice to illustrate this pattern (drawn from utterances contributed by Renato, Bibiana, Iara, Milene, and Pamela). Iara, for instance, discloses that her sister was traumatized when an HIV-positive man allegedly removed his condom during sex: “She nearly went crazy, thinking for a year that she had gotten it. Thank God she didn’t.” Fear of seroconversion also shows up in Milene’s story about a friend who “was scared to death that…I[the friend’s son] would get [HIV]” from a seropositive young woman he was dating. In order to ease her friend’s mind, Milene explained how transmission can largely be prevented (although, strikingly, she herself does not make use of these measures!).
These stories are intended to evoke sympathy for friends and family members. As such, they privilege certain bits of information, while glossing over others. A case in point: virtually all participants in this research had experienced condom failure, usually through breakage. Iara and Milene were no exception. Thus, they were aware that condoms are not a fail-safe method of HIV prevention. Yet neither woman’s narrative acknowledges this fact, or its logical corollary: that sexual contact with a seropositive person is never—biomedically speaking—entirely risk-free. Making such an observation would, in fact, run counter to the speakers’ discursive objectives by introducing the idea that the sexual partners of HIV-positive individuals are taking a calculated risk. Obviously, choosing to omit this consideration does not invalidate the experience of suffering the narratives portray; nonetheless, it is important to realize that they could have been constructed quite differently.

The uses of *pegar* in relation to others considered in this section demonstrate what, for this analysis, are the term’s most important features: its “agentic property,” which linguistically makes the person who “gets” (or does not get) the virus the focus of the sentence, and its flexibility, regarding assignations of responsibility or blame for seroconversion. This latter characteristic is particularly key to the argument being supported here. Speakers use *pegar* when talking about infected individuals who are interpreted as falling all along the continuum of responsibility; hence, there is no “default” association of this term with highly stigmatized actions or identities. Also contributing to the semantic neutrality of *pegar* is its versatility. Employed in the same way to reference colds and cancer—health concerns for which sufferers are typically not blamed—as HIV, this structural parallel can be seen as a nod toward the moral equivalence of these conditions. Together, these factors create the possibility for impartial, or even sympathetic, discussions of HIV transmission when *pegar* is used.
That being said, linguistic constructions employing *pegar* are not precluded from expressing blame or disapproval of a seropositive person’s comportment. Several utterances within this corpus of interviews attest to the ease with which this can be achieved. They also, however, reveal a noteworthy pattern: such assertions are made in conjunction with reports of transgressive or unacceptable behavior on the part of the individual in question. Further, it must be stated that these reports are not prompted by any simple correspondence to empirical facts; rather, they are interpretations, and therefore constructions of social reality, claims staked in the service of pre-existing discursive interests. This underscores the utility of *pegar* as a linguistic resource for establishing and defending identities with moral implications, like those of sanitary citizen and unsanitary subject.

Documenting this range of possible uses of *pegar* has been necessary to provide the context for understanding how members of HIV-serodiscordant couples selectively deploy the term in relation to themselves and each other. This is, I would argue, a primary discursive site at which they collaborate to construct the meaning of HIV risk, frequently in ways that differ from hegemonic, biomedical notions. Through this process of resignification, an intimate relationship once read as mortal and morally threatening is rendered a “livable love.” In terms of the semantic quarantine, we have reached the heartland that is being defended.

_Pegar in Relation to Partner_

_Pegar_ was used more frequently overall than *contamin* or *passar* when referring to one’s partner, registering 10 speech events (compared to two apiece for the other two terms). However, in contrast to the 12 participants who used _pegar_ in relation to “others,” only five referred to partners using this word. Women were more likely to do so than men (4 speakers vs. 1). In addition, when considering word use by serostatus, we find more, marked asymmetry.
Seropositive speakers applied *pegar* to partners eight times, whereas seronegative speakers did so only twice. This may seem merely logical. After all, seropositive partners already have the virus, so talk about them “getting it” might be less urgent than talk about seronegative partners potentially becoming infected (hence, the greater use of *pegar* about partners by seropositive individuals). However, there is more difference here than numbers alone indicate. While all eight partner-related uses of *pegar* by seropositive speakers were about HIV, neither of the two from seronegative speakers were. They both referred to illnesses or infections other than HIV. In addition, the tone and purpose of statements by the two groups were quite different, as explored below.

Adriano and Milene were the only two seronegative participants to use *pegar* when talking about their partners. Though neither specifically referenced HIV, their utterances, offered in the course of conversations about the effectiveness of ARVs, were strikingly similar. Adriano, commenting on the extent of Rita’s health problems, remarked: “It’s like she’ll get a little cold, and sniffle and cough for three, four days.” In response to a probe about whether this was normal, he offered himself as a standard of comparison: “Sometimes I get a cold and I’m sick for longer than she is.” Similarly, Milene claims that she’s not necessarily healthier than her partner. When asked if she worried about getting HIV, she claimed not to, given the efficacy of available medicine. “It’s like I said to [Renato], ‘I get sick a lot more than you!’ He gets a cold, but he gets colds because he likes to take a shower right before he leaves the house.” Both utterances focus on respiratory infections—a common winter ailment in Porto Alegre, given the city’s temperate (as opposed to tropical) climate—and juxtapose the speakers’ own health to their partners’ in an explicit attempt at normalization. Rita’s symptoms, Adriano suggests, are the same ones anyone suffering from a cold would experience. Likewise, Milene implies that
anyone behaving the way Renato does would get a cold. Thus, these illnesses are portrayed as remarkable in neither causality nor duration.

On the surface, then, what Adriano and Milene say seems to support the discourse of normality: people with HIV, just like anyone else, occasionally catch a cold. They may sneeze and wheeze a bit, but then they get better. HIV doesn’t come up; the speakers seem to imply it’s irrelevant. And yet, as with most instances of the discourse of normality, though it may not be immediately apparent, HIV still plays an important role in structuring these utterances. In fact, their full meaning can only be appreciated when we unearth an implicit contrast on which both are predicated: good health despite serostatus. More specifically, these statements respond to and are designed to contradict an assumed expectation that the virus would render the seropositive partner’s health fragile. Absent such a presumption, what would be the basis for a priori predictions about the relative health of the members of the couple, or the urge to set the record straight? Thus, HIV, while unspoken, is nevertheless influential.

Such considerations highlight the multiple levels on which participants’ speech much be considered. Most obviously, we must attend to what is said; it is significant that Adriano and Milene say their partners are in good health. Saying they “get” every little illness that comes along, or that they get colds every winter and have difficulty recovering, would represent an entirely different reality. Although characterizations of partners’ health may be colored by the speakers’ own desires that Rita and Renato remain healthy, I take these reports to reflect Adriano and Milene’s true perceptions (the accuracy of these perceptions was evaluated through triangulation: observation of the partner, and/or monitoring serological indicators, like CD4

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96 Translator’s note: meaning he leaves with hair still wet. Many Porto Alegrenses stated that being outside with wet hair in the winter causes colds—irrespective of HIV status.
count and viral load). Methodologically speaking, this level of meaning could be assessed through one-time interviews or perhaps even open-ended survey questions.

Other, deeper levels, however, reveal the strength and necessity of an ethnographic approach to discourse analysis. For example, there is what is not said. In this case, the fact that no seronegative individual ever used *pegar* to talk about how his or her partner became infected with HIV takes on heightened importance because of the multiple opportunities they had to do so. They did not simply run out of space on a questionnaire, or time during an interview. Hence, when confronted with the question of how to interpret this lack of talk, there is ample reason to see it as meaningful, even if not necessarily the product of a conscious choice. In addition, as in the analysis offered above, sometimes one must consider not only what is said and what is left unstated, but also the possible relationship between them. Grasping the meaning that can be drawn from these levels is challenging precisely because silence implies a certain “flatness” that provides few toeholds for analysis. A lack of speech, therefore, is open to various interpretations; an ethnographic approach allows one to bring other observed patterns and dynamics to bear on gauging the explanatory fit of each one.

Because “*pegar* with relation to partners” is conceptualized as a fundamental component of the semantic quarantine, the supporting evidence from which the conclusions drawn in this analysis are based deserves succinct restatement. First, seronegative speakers only very rarely use *pegar* in reference to their partners. Second, when they do so, it is not to talk about HIV. Third, uses of *pegar* were intended to demonstrate HIV’s irrelevance to the seropositive partner’s health—that is, to normalize it. Fourth, despite that explicit message, the deep structure of both examples in fact illustrated that HIV continues to make a difference—not in terms of the
seropositive partner’s health *per se*, but in what his or her health means (not simply “good,” but “good, in spite of”).

These observations taken together suggest that, at least in terms of what they were willing to say to this researcher, how the seropositive partner contracted HIV is a taboo topic for seronegative speakers. That this taboo does not apply to seroconversion more broadly, however, is evident, as seronegative partners are by no means reticent when discussing how others became infected. In addition, the restriction also seems not to extend to the seropositive partner’s HIV status in general, since seronegative speakers can and frequently do talk about the lived experience of infection (as they perceive it for their partner, or as experienced jointly). This talk usually doesn’t employ *pegar*, but often involves commentary on adherence to and efficacy of pharmaceutical regimens, or other ways the partner can be seen as living “normally” with HIV. Thus, what is “unsayable” in reference to the partner involves behaviors that that have the potential to classify him or her as an unsanitary subject; more permissible are constructions that position him or her as a sanitary citizen.

Less reading between the lines is required to make sense of seropositive speakers’ statements. Three females use *pegar* to refer to their seronegative partners on eight separate occasions. Fear, worry, and distancing dominate these utterances. Although each is unquestionably discussing HIV, no speaker says “HIV,” instead relying on words like “the virus,” “the disease,” and even just “something” when they specify what they so fear their partner “getting.” Iara, for example, says, “It really was very lucky, you know, Shana, that he didn’t get [it].” Rita is more explicit as she explains her greatest stress or fear over the week preceding the interview: “Honestly, what worries me most is him, you know? Him being sick or getting the virus.” Sometimes this fear is attributed to the partner, as when Bibiana says,
“Felipe—I don’t know. I think he’s afraid, like even just leaning on me he’s going to get something, understand?”

Distancing is also a prevalent tactic. This takes various forms, as when Rita reports Adriano’s decision about how to deal with disclosing to his family, in the event of his hypothetical seroconversion. He would simply “say that [he] got [it] from someone else,” which distances the infection from her. Iara on the other hand, distances her partner, Jorge, from his initial inclination to refuse condom use by emphasizing his mental state: “It was just in the beginning, when he had that crazy desire to get the disease and he didn’t want to use them.” Finally, Bibiana invokes distance more directly when she claims: “I feel he’s very distant from me, ok? That seems like it has something to do with him getting some disease, or something.”

The striking element that these segments share is the way they make use of the agentic property of *pegar*. In each case, the active role in seroconversion is linguistically accorded to the seronegative partner. In most cases, the seropositive partner’s role is omitted entirely, as when Rita says, “Honestly, what worries me most is him, you know? Him being sick or getting the virus.” Were the listener unaware of the speaker’s serostatus, the perceptible fear of infection could be perplexing, to say the least. Occasionally, the speaker’s involvement in the situation breaks through, but in equivocal ways. Bibiana says about Felipe, for instance, “He thinks that if he kisses me on the mouth he’ll get the disease, you know?” Felipe’s agency is unmistakable. He will kiss her on the mouth, or he won’t. He will get the disease, or he won’t. What role, if any, Bibiana will play in this is ambiguous. Each speaker also avails herself of the flexibility offered by *pegar* to avoid suggesting that seronegative partners bear any blame or responsibility for possible transmission. Given the previous pattern established with respect to such
attributions—namely, that they occurred only when the speaker also highlighted immoral or transgressive behavior—this is unsurprising, but still significant.

Overall, the way seropositive speakers use *pegar* allows them to linguistically shed responsibility for their partners’ possible seroconversion, while expressing concern but avoiding suggestions of blame. Seronegative speakers collaborate in this project through a lack of talk about the seropositive partners’ seroconversion, and attempts to normalize seropositivity. Together, these strategies serve to minimize the cues that might trigger stigmatizing associations and the ascription of an unsanitary subject identity—at least for the infected partner. The next section, which deals with self-referential uses of *pegar*, provides further evidence that this can be interpreted as an important, if subconscious objective of the couples’ talk. Like a mirror image, each group’s use of *pegar* to refer to themselves reinforces the strategies the other deployed with reference to partners. Seropositive speakers rarely use *pegar* to talk about their own seroconversion, focusing instead on other diseases. Seronegative speakers play a particularly important role. Acquiescing to the discursive moves that make them responsible for HIV transmission within the couple, linguistically they portray themselves as having an active role. They use *pegar* to talk about this eventuality far more than they used any other term.

**Pegar in Relation to Self**

Seropositive speakers used *pegar* in reference to themselves during only five speech events, and three of those utterances weren’t specifically about HIV. Renato, in fact, explicitly denies that the virus has any negative physical impact on him. When asked to rate his overall health, he chose “excellent,” explaining, “As you can see, it’s just work accidents, or a cold that I get, but that doesn’t have anything to do with me being ‘soro’.”

Indeed, Renato had told me

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97 “Soro” is a word several participants used to mean “seropositive.”
that even when he’d stopped taking his medication in the past, he’d never developed any symptoms, other than the herpes outbreak that led to his diagnosis in the first place. Thus, his assessment of his health echoes his partner, Milene’s (cited above), and fits in with his multiple statements about being able to conduct his life “normally,” despite HIV.

Bibiana and Iara, perhaps because they are more newly-diagnosed, do not share Renato’s confidence. Bibiana repeatedly mentioned her concern that her compromised immunity would lead to health problems. Specifically, she worried that “everything that happens to me will be faster than it is in other people. If I get a cold, if I get a disease, if I go out in the rain.” Iara was acutely aware of how devastating immunodeficiency could be, having been hospitalized for nearly a month with a CD4 count of 34 upon diagnosis with HIV. She cringed when asked how her situation might be different without access to ARVs and answered, “Just imagine if I got other diseases? The opportunistic ones.” With relatively little experience of living with the virus, and incredibly traumatic circumstances surrounding their diagnoses, these women assess their health differently than Renato does.

One truly remarkable finding from this discourse analysis is that only Bibiana used *pegar* to talk about how she acquired her infection. As described in the section, *Contamin*: The Sound of Silence, she claimed to feel much more anxious about revealing her past sex work to her daughter than her HIV status, since sickness was something that could happen to anyone. She uses *pegar* as she explains, “I could have gotten [HIV] from [my daughter’s father], just like I could have gotten it [from a client], you know?” Infection, however, remains hypothetical here; it focuses on what could have happened. Later in the same interview, however, Bibiana gets specific. In the midst of a discussion about conditions favoring transmissibility of the virus, she noted, “The person I got it from must not have been in treatment. I know who it was, Shana. A
guy who disappeared.” She goes on to talk about one of her past CSW clients who suddenly lost a substantial amount of weight, went through a divorce, and stopped answering her calls. Although she admits she can’t be certain of his serostatus, she says, “I think everything points to it being him, you know?”

That Bibiana is the only seropositive participant to use *pegar* to discuss her own seroconversion is surprising. Given the term’s default neutrality regarding responsibility or blame, and seropositive speakers’ frequent application of *pegar* to their partners, one might have expected it to be the word of choice for them in talking about themselves as well. *Contamin*, after all, was discursively too dangerous to employ self-referentially, with only Xavier’s special case permitting him to use it. *Passar* was also not a popular choice, with only Iara making use of its “directional” property to explicitly hold the person she believed infected her responsible. Since every seropositive participant in this research was asked how they came to be HIV-positive, if they didn’t use *pegar*, how did they respond? And how does their word choice relate to the semantic quarantine?

The short answer is, they responded obliquely, without recourse to words that were commonly used to talk about the seroconversion of other people. As already noted, Renato never stated that he acquired HIV from a contaminated needle or injection equipment in the hospital; he relied on the listener to fill in relevant details, thereby avoiding putting the incident into words. Others used similar strategies. Rita was asked directly, “Do you know how you became infected?” She answered, “Actually even I don’t know. I don’t know if it was from that guy I was with for six years, because he cheated on me a lot.” Later, she added another possibility: “I was with two men after that, ok? And I didn’t protect myself either.” These, according to Rita, are the only possible routes by which she could have become infected, but she
never says, for example, “I got HIV from unprotected sex,” which would be the clearest way to answer, and—if we take her at her word—accurate as well. Neither is there any reliance on *passar* or *contamin*; Rita answers the question with a minimum of articulation, in stark contrast to the way she responded to queries about “others.”

Wílian also avoids putting the actual behavior that led to his seroconversion into words. When asked, “How did you find out you were infected?” he prefaces his answer with the observation that many people in Porto Alegre were being diagnosed at the time. This prompted him to seek out testing fairly regularly. As he put it, “You know how single men are—they go out with one woman, then go out with another, right? One of the last tests I did came out positive.” Hence, neither Wílian nor his individual actions are the focus of this sentence—linguistic agency is attributed to “single men” and the HIV test itself, which “came out positive.”

It was suggested in the section on *contamin* that Renato and Rita’s discursive strategy of eliding the mechanics of seroconversion might be an attempt to minimize its impact. In addition, although both clearly felt themselves to be victims in terms of HIV transmission, neither used *contamin* to emphasize this status. Instead, both preferred to advance a different identity: as “normal” in Renato’s case, as a “good” woman in Rita’s. Wílian’s self-portrayal also highlights ways he adheres to gendered norms for sexual behavior and thereby rejects an HIV-related identity.

But the evident reluctance of these seropositive speakers to use *pegar* to refer to themselves goes further than the non-use of *contamin*. In part, it is the refusal of the same linguistic agency in connection with HIV transmission that they insist their seronegative partners assume. Despite the fact that stigmatized identities are more tenuously associated with *pegar* than with other commonly employed terms, assuming any responsibility for infection appears to
pose too great a risk of introducing unsanitary subjecthood for those who already have the virus. As such, the absence of self-referential utterances using *pegar* can also be interpreted as an analog of the taboo on seronegative speakers’ discussion of their partners’ seroconversion. To be clear: members of serodiscordant couples are not in denial, as such, because there is an abundance of talk about HIV and its consequences from both partners, but the interaction or moment of infection stands as so potentially stigmatizing that it is, discursively, too powerful and dangerous to name.

Of course, this taboo—like all taboos—is not unbreakable. Explicitly referring to seroconversion is not impossible, but, it would seem, only permitted under certain circumstances. Within this corpus of texts, we have what can be boiled down to two classes of examples. First, when Xavier uses *contamin* to talk about seroconversion, he makes a clear distinction between his past and current self. In essence, when he does so, it is as though he is using *contamin* to refer to someone else, to an “other.” Such uses are much more common, especially among seropositive speakers, than self-referential ones. This makes sense; the taboo does not apply to talk about how others’ contracted the virus.

Second, we have Iara and Bibiana, who use *passar* and *pegar*, respectively, in explicit reference to their own seroconversion. Although the directionality of these verbs can be read as indicating Iara’s refusal to place herself in an active role in acquiring the infection, while Bibiana accepts this linguistic attribution of agency, what they have in common may be more important than this difference. Their utterances both name something that other seropositive speakers do not; these two women violate the taboo. As mentioned previously, they are also much more recently diagnosed than the other participants, and that diagnosis was something they were both still clearly trying to assimilate. It was rare for any extended conversation with Iara that
broached HIV not to include a discussion of her hospitalization. Likewise, Bibiana’s regret over terminating her pregnancy, and her preoccupation (despite her disavowal of these fears) with her health were themes that recurred predictably. Neither seemed entirely convinced of the likelihood that they could still experience decades of life—let alone “normal” life. We might, for this reason, see Iara and Bibiana as not having (fully) emerged from a liminal state produced by the physical and emotional trauma their diagnoses occasioned. They have not yet fully re-integrated themselves into the kind of lives they led before—that is, they have not achieved reincorporation. As expected for those experiencing liminality, customary rules—in this case, the taboo on explicit talk about seroconversion—do not apply. These two women, by virtue of their temporal and experiential proximity to the tabooed event, are “beyond…the conceptions of behavior, rule, time and space” (Rappaport and Overing 2007:263). They are free to say the unsayable.

In this way, their status differs significantly from Renato, Rita, and Wílian’s, as the latter were all entering, or well into, their second decade of surviving HIV. None experienced the lingering malaise that dogged Iara, or the sense of a future lost that haunted Bibiana. Having proven to themselves and their partners that their physical health need not be a source of continual worry, they have been reincorporated, and hence must observe the taboo. They are confronted with this discursive restriction precisely as negotiating the social aspect of their serostatus becomes a priority. A stable CD4 count frees them to deal with the demands of identity construction, which, as Alicia Arrizón (1999:xxi) reminds us, is “dynamic and forever in process….Identity, like culture, is never static. It is a phenomenon always in transition.” Thus, while ARVs have restored their physical selves, their social selves are in constant need of attention, which, for these three seropositive individuals, entails distancing themselves from
stigmatized identities. The paucity of statements that use pegar to refer to their own seroconversion thus constitutes an integral part of the semantic quarantine.

This linguistic denial of serological responsibility is reinforced by seronegative speakers’ marked reliance on pegar to refer to themselves. Four individuals used pegar in this way in 14 separate speech events, making such usages much more common than those employing contamin* (two individuals who contributed just three speech events) or passar (one speech event). In contrast to the way seropositive speakers used pegar to refer to themselves (or the way seronegative speakers used pegar to refer to their partners), seronegative speakers’ self-referential uses of pegar were virtually always about HIV transmission. In only one speech event was HIV not the focus of the utterance.

The thirteen speech events that are references to HIV do not generally name the virus, however. What the speaker may or may not “get” must usually be inferred from earlier statements. The only speech event in which the speaker actually says “HIV” is one in which Milene discusses unprotected sexual contacts that she had in the past. She said she was lucky to have simply become pregnant from these encounters: “Instead of that, I could have gotten HIV or I could have gotten—which I think are more horrific than HIV—those diseases [STIs] that we see out there.” Thus, even as Milene names the virus, she downplays its impact or meaning, framing other possible consequences of unprotected sex as worse.

This is not to say that HIV is constructed as without negative consequences. Milene admits, for example, “I have the impression that, for me, if I get it, my [physical state] will worsen.” This, however, is not intended as a general statement about seroconversion. Rather, her supposition is largely due to the obligatory hyper-vigilance she directs to her own body, as a consequence of other, at times debilitating health problems. She explains that she has to be
cognizant of even small alterations in her condition in order to complete necessary housework. Adriano also comments on the possible effects of contracting HIV, although his utterance is presented as at least partially facetious. In the course of praising Rita for her dependable and precise adherence to her ARVs, he comments, half-laughing, “I told her, if I get it someday, I’m going to die…because I’d forget [to take the medication].” As usual with Adriano, it’s an open question to what extent a joke is motivated by a desire to mask anxiety, and how much to attribute to his jocular personality. In any case, Rita immediately contradicts him, saying she would help him remember.

The most common way seronegative speakers applied pegar to themselves, however, focused not on hypothetical consequences of transmission, but reflections or explanations about non-transmission. This was the theme of seven speech events. Adriano offered three statements of this kind, some of which have already been discussed in this chapter. In the first utterance, he suggested that, along with his tendency not to dwell on possible negative consequences, his “love for [Rita] keeps [him] from getting it.” On two other occasions, he contemplates an additional protective factor: "How many times have we had sex without a condom and I didn’t get it. So I feel like it could be that she has it and it’s incubated, and she doesn’t pass it to anyone.” Several months later, on one hand he sounds more certain, saying, “What she’s got is incubated in such a way that I’m not getting it” (literally, “it’s not getting on me”). On the other, he makes this comment while noting that he feels the time has come for him to get tested for HIV again; he does so every few months.

Milene also was tested for HIV during the course of this research—but according to her, she did this in order to have “proof” for me that she remained seronegative. She echoed Adriano’s notion that an HIV-infected partner with “good immunity” (i.e., one that is on
effective therapy) cannot transmit the virus: “I think that’s why I don’t get it from Renato. His
[immunity] is always good. The doctor always praises him, you know?” Juliana also picked up
on this same theme of non-transmissability, with her partner’s doctor allegedly playing a more
direct role:

Juliana: I’ve been with [Xavier] for eight years and thank God— Well.
His [disease] is paralyzed, you know?
S: Yes, his viral load is very low.
Juliana: So there’s no way [for transmission to occur]. Like the doctor
said. But I could get hepatitis [C]…But I don’t get that either.

In the above segment, Juliana offers an explanation of why, after years of unprotected
sexual contact, she has never seroconverted: because Xavier’s virus is “paralyzed.” My
affirmation of her statement was intended as a potential jumping off point from which to explore
her understanding of biomedical terminology; many participants used terms like “CD4 count”
and “viral load” (albeit sometimes imprecisely), and some asked me detailed questions about
what the results meant, or how these tests related to each other. Juliana, however, had never
phrased her statements about HIV in such clinical language, and I was curious how she would
respond. She chose instead to forego this tangent and continue the story she’d been telling, about
her physical inability to use condoms, that had prompted her comment on Xavier’s viremia. She
not only concludes that, under such conditions, transmission is impossible, she attributes this
notion to a doctor, as if to bolster the credibility of the assertion. Then, however, she seems to
call the relevance of such considerations into question by noting that the same behaviors that
expose her to HIV could also lead to infection with Hepatitis C—which she also has never
gotten.

Discerning the reason for her continued seronegativity seems of precious little
consequence to Juliana, since, as described in the couple sketch, she claims not to fear HIV
infection—or anything else, for that matter. After suffering heart attacks and threats of stroke,
she says life and death are questions she leaves to God. Or luck. In her other self-referential use of *pegar*, the availability of treatment for HIV turns seroconversion into mere “bad luck.” She says, “If for some reason I have the bad luck to get it, what is it that I’m going to do? Start doing the treatment. That’s the only way, because what am I going to do? Leave? I’m not going to leave. After seven years with him? I can’t just abandon ship.” Of course, we know that Juliana does eventually “abandon ship,” but that her decision is motivated by other concerns (Xavier’s more frequent drinking, possible infidelity, etc.). If it ever had been, at the end of Juliana and Xavier’s relationship, HIV was not a determining factor.

While Juliana, Milene, and Adriano primarily use *pegar* to explain why they cannot contract HIV from their partners or to minimize the import of potential transmission, Felipe’s utterances do not fit this pattern. Instead, he is the only seronegative speaker to employ *pegar* in association with doubt and fear when in reference to his own personal situation. In describing the impact of Bibiana’s diagnosis on the couple, he says “She was afraid that I had… I had gotten it too.” Felipe’s hesitation in this statement mirrors that found in the example cited earlier in which he applied *contamin* to himself. In that instance, he said, “Even when I could have been contaminated, I didn’t…I didn’t think much about that.” Because this is not characteristic of his speech pattern in general, it suggests a topic-specific reticence or caution. It is also notable that in both examples, Felipe disavows distress on his own part in relation to his exposure to the virus. He does attribute this reaction to Bibiana—who, interestingly, claims she senses that her partner’s fear of transmission is profoundly affecting their intimate relationship.

Later in the same conversation, Felipe mentions the year-long period in which he and Bibiana did not use condoms while she was presumably infected, then concludes, “That’s why I’m telling you that I couldn’t understand how I didn’t get it too.” Although other seronegative
speakers remarked on the persistent serodiscordance of their relationship, they also eventually offer at least one explanation for it. Felipe never does. For Milene, Juliana, and Adriano, the three HIV-negative members of couples who do not consistently use condoms, the non-transmissability of HIV (under certain conditions) is part of this explanation. For Felipe (and for Bibiana, incidentally), in contrast, HIV is constructed as imminently transmissible, thus his seronegativity is an unsolved mystery.

Despite this important difference, on a fundamental level Felipe’s use of *pegar* contributes to the semantic quarantine in the same way all the others cited in this section do. By making himself the active agent in linguistic constructions about getting or not getting HIV, he deflects potential focus from his partner. As argued in the foregoing analysis, seronegative speakers demonstrate such a pronounced tendency to communicate about HIV transmission in this way that it cannot be accidental. Further support for this idea is again supplied by what is not said. Taking Felipe as an example, it’s significant that he said, “I couldn’t understand how I didn’t get it too” rather than “I couldn’t understand how I didn’t get it from her.” Indeed, in only one speech event do these speakers ever specify the source of the infection. The fact that this occurs exclusively when Milene explains why she cannot get HIV from Renato should be seen as strategic. Other than this reference, the only suggestions of any type of causality in relation to potential HIV transmission are “bad luck,” and—only implicitly—unprotected sexual contact. But this latter action is rendered as *a gente já transou*, or “we already had sex” (in spoken Portuguese in Porto Alegre, *a gente*—literally, “the people”—means “we”), a construction in which both individuals figure as willing participants. Seropositive partners are thus shielded in multiple ways from any hint of responsibility.
Semantic Quarantine in Review

Now that data for all categories of use for contamin*, passar, and pegar have been presented, a more focused discussion of how speakers selectively pull from these linguistic resources to effect the semantic quarantine is in order. Although detailed consideration of how such terms were applied to third-parties was necessary to provide a frame of reference for interpreting the intra-couple uses, in this section the focus will remain on the couple. To briefly summarize, contamin*, passar, and pegar are all used in this corpus of texts to refer to HIV transmission. It’s even possible to use any of the three terms to communicate the same serological relationship (i.e., She contaminated him vs. She passed HIV to him vs. He got HIV from her), but the meaning of the resulting phrases in terms of stigma and blame is drastically different.

Contamin* is rarely used by participants in this research, and only in relation to HIV. It is notable for its bifurcated meaning. Depending on how it is used/conjugated, it can convey either a clinical transmission, for which the infected individual should not be held responsible, or, in non-clinical contexts, it can carry the heaviest expression of culpability for the person responsible for transmitting the virus. Translating as either “infect” or “contaminate,” it clearly evokes pollution and stigmatized identities, which are incompatible with Brazilian notions of couplehood. As such, it is usually not applied within the relationship; this protects the speakers, their partners, and their union, from its negative associations. A handful of cases in which this term was used clearly demonstrated its power. Its use marks the discursive death of the “old Xavier,” and sends powerful shock waves through Rita and Adriano’s relationship; Iara

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98 Of course, there are societies, well known to anthropologists, in which heterosexual coupling occurred amidst precisely this kind of antagonism. In many Melanesian groups, for example, consensus exists—or existed?—as to the danger women posed to men via menstrual pollution (Wardlow 2006, Wormsley 1993). Brazilian ideals of couplehood, however, are very different.
employs it as a disciplinary mechanism to obtain compliance from her partner regarding condom use. Also important to note about contamin* are the instances in which participants—even those who might have benefitted from the victim identity it facilitates—avoided the term in their narratives. Seropositive speakers in particular were apt to position their infection as the result of adherence to valorized gender norms, which can be interpreted as an attempt to evade identification with an unsanitary subject identity.

*Passar* was used more frequently and flexibly than contamin*. This flexibility was both topical and affective. *Passar* was occasionally used to refer to health problems other than HIV, and most speakers demonstrated more varied emotional responses while using it than was the case with contamin*. *Passar*, in the sense most relevant to this study, is notable for its “directionality,” that is, the emphasis it places on the sender or source of infection, as well as its less negative and medicalized connotations when compared to contamin*. Perhaps for these reasons, seropositive speakers far preferred it to the latter term when talking about themselves. Renato, Rita, Iara, and Bibiana, for example, all used passar in reference to their role in their partners’ possible seroconversions; usually these mentions were characterized by anxiety or fear. The term was also employed in place of contamin* when the speaker had a caring relationship with a third party capable of transmitting the infection, as was the case with Bibiana and her ex-husband, and Milene and a seropositive young neighbor. This is in accordance with what the dynamics of the semantic quarantine would lead one to expect.

What confounded expectations was the marked non-use of passar in relation to partners—by speakers of both serostatuses. While seropositive speakers might be seen to have less need of this term in relation to their current partners (who are included in this research precisely because they have nothing to “pass”), it was anticipated that seronegative speakers
would make use of it in reference to the possibility that they would become infected. That they largely did not constitutes an important component of the semantic quarantine. Doing so would have made their partners linguistically responsible for intra-couple HIV transmission, calling attention to them as agents of infection. This, in turn would have opened the door to a host of undesirable associations and potential classification of the partner as an unsanitary subject. A desire to avoid this leads seronegative speakers to articulate their statements about possible seroconversion differently.

Specifically, they rely heavily on *pegar*. As articulated previously in this chapter, by choosing particular words over others, speakers are able to change the meaning of the acts or events being discussed. In terms of the way *pegar* figures in the semantic quarantine, it has two characteristics that make it a strategic resource. It can be applied to individuals who fall at various points along a continuum of responsibility for infection, so its “default” connotations in this regard are the least stigmatizing of the terms discussed here. In addition, what I’ve called the “agentic property” of *pegar* is the flip side of *passar*’s directionality; *pegar* focuses on, and thereby attributes the active role in HIV transmission to, the individual acquiring (or not) the infection. This can easily result in the source of the virus becoming superfluous to the sentence, which tends to suggest its irrelevance to the real-life situation about which communication is occurring.

This is precisely what happens when seronegative speakers discuss HIV transmission. Because they use *pegar* to say “If I get it…” rather than *passar* to say, “If s/he passes it to me…”, for example, their seropositive partners almost always drop out of these utterances altogether. Linguistically, the process appears to unfold without any involvement from the infected partner at all because the seronegative partner, grammatically, assumes all
responsibility. Seropositive speakers reinforce this dynamic by frequently using *pegar* to put their partners in an active role when possible transmission comes up in conversation. As this translates to the quarantine metaphor, the seropositive partner is kept safely in the center of the space that has been discursively cordoned off from all non-sterile linguistic constructions; the seronegative partner patrols the periphery.

This configuration is reinforced by the existence of a taboo on speech about the seropositive partner’s own seroconversion. This silence is another component of the quarantine that couples collaborate to enforce. Seropositive members of serodiscordant couples very seldom use *pegar* to talk about their own HIV infections; they are more likely to employ the term in reference to other health issues they may experience. They are also likely to avoid putting the particular interaction or event that led to their seroconversion into words of any kind, relying on the interlocutor to fill in holes in their narratives. Seronegative speakers likewise do not use *pegar* to discuss this. In fact, they rarely use *pegar* in relation to their partners at all, and when they do, it is to talk about—and attempt to normalize—other aspects of the seropositive loved one’s health.

The tables below show how speakers collaborate to enforce the semantic quarantine, and particularly this taboo. The first table displays the 28 speech events in which seropositive (SP) and seronegative (SN) participants used *contamin*, *passar*, and *pegar* self-referentially. The overall frequency (far right column) with which each term was used indicates a clear preference for *pegar* over the other two. This same pattern appears in the speech of seronegative participants; *pegar* accounts for 12 of the 16 self-related speech events (although a small portion of these were about illnesses/infections other than HIV). Such is not the case for seropositive speakers, however, who used this group of terms to talk about themselves less frequently overall.
(compare two middle cells on bottom row) than their partners did. They were more likely to use *passar* than *pegar* in such speech events, and very unlikely to use *pegar* to discuss HIV.

Table 6.5: Semantic Quarantine, Self

<table>
<thead>
<tr>
<th>Term used in reference to self</th>
<th># of speech events from seropositive participants</th>
<th># of speech events from seronegative participants</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Contamin</em></td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><em>Passar</em></td>
<td>7</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td><em>Pegar</em></td>
<td>4 (3 non-HIV)</td>
<td>12 (1.5 non-HIV)</td>
<td>16</td>
</tr>
<tr>
<td>Total</td>
<td>12 (3 non-HIV)</td>
<td>16 (1.5 non-HIV)</td>
<td>28</td>
</tr>
</tbody>
</table>

The second table, which displays partner-related uses of *contamin*, *passar*, and *pegar*, presents both commonalities and contrasts with the first. There are fewer speech events overall (just half the number represented in the first table), but an even more pronounced preference for *pegar*. This time, the seropositive speakers’ contributions conform to the general trend; they are more likely to use *pegar* than the other two terms in reference to their partners. They tally almost as many speech events discussing their partners as themselves—more, in fact, if only HIV-related utterances are included. The glaring difference between the two tables becomes evident when considering seronegative speakers’ contributions. Whereas seropositive speakers employed *contamin*, *passar*, and *pegar* to talk about their partners 11 times—all in reference to HIV—seronegative speakers did so just thrice, only one of which was about HIV. This is the unmistakable effect of the taboo on reference to the seroconversion of seropositive members of the couples.
Why is this taboo so integral to the semantic quarantine? Why, if the purpose of these discursive strategies is to protect the couple from being ascribed stigmatized identities, do seronegative speakers so willingly assume linguistic responsibility while their partners grammatically cut and run? Part of the answer to these questions is that it is less risky to take responsibility for a non-event, that is, something that hasn’t happened. In fact, a number of seronegative speakers’ uses of *pegar*, for example, are statements about why transmission cannot occur. This is akin to taking responsibility before-the-fact for a potential head-on collision when the lanes of oncoming traffic are separated by a median a quarter-mile wide; accidents are possible, but not likely. Another factor at play, however, is that seronegative speakers need a shield from HIV-related stigma less than their partners do—they have recourse to the ultimate defense in this regard: they don’t have HIV. Seropositive individuals are much more vulnerable to being branded as unsanitary subjects. The proof, at least according to wider Discourses, is in their serostatus.

Seropositive members of HIV-serodiscordant couples may appear, from the foregoing discussion, to have more at stake in these discursive re-imaginings than their partners. That may be true if we focus only on the identities likely to be attributed to each person should the semantic quarantine fail. The larger issue, however, is the survival of the relationship, something in which—ideally—both partners are equally invested. For the union to endure, associations of

Table 6.6: Semantic Quarantine, Partners

<table>
<thead>
<tr>
<th>Term used in reference to partner</th>
<th># of speech events from seropositive participants</th>
<th># of speech events from seronegative participants</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Contamin</em></td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td><em>Passar</em></td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td><em>Pegar</em></td>
<td>8</td>
<td>2 (both non-HIV)</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>11</td>
<td>3 (2 non-HIV)</td>
<td>14</td>
</tr>
</tbody>
</table>
HIV with blame, stigma, and danger must be excluded from the couples’ everyday interactions. Maintaining the kind of intimate bond idealized in Brazilian notions of heterosexual couplehood seems highly unlikely if one or both members see themselves as waking up every morning in the midst of a mortal threat. Alternative meanings for the risk of HIV transmission must be found, responsibility for it shared, and this new interpretation of life normalized for love to be livable. For this reason, it is imperative that the semantic quarantine be a collaborative effort. Neither individual could effect such a profound reconstruction of reality alone.

**Conclusion**

This chapter extends the holistic vision of serodiscordance anchored by the preceding couple sketches (Chapter 5), employing discourse analysis to this end. This approach was taken for two reasons. First, the political economic framework envisioned for this dissertation did not account for the variation in the data or shed light specifically on the construction and negotiation of risk. Second, I agree—at least in some situations (see Wight and Barnard 1993)—with Quinn (2005:3) that discourse “is the best available window into cultural understandings and the way that these are negotiated by individuals.” While the sketches speak to the place HIV occupies in the everyday lives of participating couples, this chapter has drawn from multiple interviews and participant-observation sessions with the aim of answering this dissertation’s primary research question: How is risk, specifically the risk of HIV transmission, constructed and negotiated in the daily lives of a sample of heterosexual, HIV-serodiscordant couples in Porto Alegre, Brazil?

The analysis reported in this chapter begins by carrying forward an idea found in the couple sketches, namely that of HIV’s relative unimportance. A close consideration of the data revealed a highly consonant group of expressions that echoed previous findings from the literature. Specifically, these expressions related living with HIV/AIDS to “normal life,”
constituting what I call the “discourse of normality.” This discourse provides rich material for “thinking about what and how social activities and socially situated identities are being enacted and/or recognized” (Gee 2005:115). Analysis reveals that, although members of these participating couples often claim to have “a normal life,” the implicit referent in such constructions is—consistently—the condition of seronegativity. Although speakers adopt diverse positions as to whether “a normal life” is truly possible for seropositive people, and what moral meaning should be attributed to any deviation from normality, what is “normal” is invariably valued. In terms of understanding these couples’ constructions of HIV, the discourse of normality clearly exhibits the influence of hegemonic ideas that imbue positive serostatus with stigma. I interpret this as a reflection of “cultural presuppositions,” which, as Quinn notes (2005:17), lie “largely beyond the conscious control of the speaker.” That these presuppositions, however, are expressed even by seropositive people and those who love them demonstrates the profundity of HIV-related stigma, and, hence, the necessity of measures to combat its effects within serodiscordant relationships.

Moving on from the discourse of normality, a case study of the discursive production of one participant, Xavier, around the topic of HIV transmission highlights connections between linguistic practices, stigma, and non-serostatus related identities. Similar patterns were found in the discourse of other participants; hence, the remainder of the chapter focuses specifically on talk about HIV transmission as a window onto constructions of risk. Specifically, various permutations of three key terms, contamin*, passar, and pegar, were examined and found to be

And here I would follow Persson’s (2011:570) lead and further stipulate that the seronegative members of these couples, despite their ostensible serostatus, are, in fact, not part of this unmarked “reference group.” Their intimate relationships with seropositive people do leave them in a liminal state: not “normal,” not seropositive.

Indeed, this variation occurs not only across the individuals in the sample, but also within the body of utterances produced by one speaker. Bibiana, for example, voiced contradictory positions, as did Renato.
consistently deployed in ways that reveal how these couples construct HIV risk, such that biomedical and other hegemonic interpretations of the serological reality posed by serodiscordant unions are resignified. The purpose of such re-imagining is nothing less than to preserve the viability of the relationship, which otherwise would be threatened by the introduction of tensions incompatible with intimacy. These include the still-prevalent notions that only members of what were once conceived as “risk groups” contract HIV, and that—as a corollary—those diagnosed with HIV must have engaged in immoral behavior and are therefore seen as having brought the infection on themselves.

In order to safeguard their bond, couples stake claims to other, valorized identities. They also collaborate to create a discursive space where popular associations with HIV do not apply to them, if they are allowed to enter at all. They employ a suite of linguistic strategies to enforce what I call a “semantic quarantine,” that is, the discursive isolation of the relationship or its constituent members from stigmatizing lexical elements. Though participants apply the words considered in this analysis in a range of ways when referring to “others,” as a general rule, the most derogatory potential uses of any term are avoided in reference to people with whom one has a personal relationship. This tendency is particularly pronounced when members of the couple talk about themselves or their partners, illustrating the effect of the quarantine. At its most extreme, the quarantine results in a taboo on discussing the seropositive partners’ seroconversion. Of paramount importance is to avoid linguistic constructions likely to activate negative associations that, in turn, might raise the specter of the “unsanitary subject,” an identity both members of the couple strive to evade.

In terms of a succinct answer to the overarching research question this chapter addresses, the findings confirm those suggested by the couple sketches. Just like the concept of
“serodiscordance” itself, neither HIV nor the risk of contracting the virus are monolithic in their meaning. Rather, they are contingent and cannot be understood in isolation from either the larger social context in which they occur, or the special parameters imposed by the sexual-affective condition of couplehood. It is true that scientific advances and the ideological and legal structure of Brazil’s public health care system have rendered the biomedical management of HIV/AIDS relatively unproblematic for the seropositive participants of this research. But despite this inspiring achievement (and, truth be told, perhaps in part because of it), these data suggest that, for HIV-serodiscordant couples, the most worrisome source of “contagion” is sociocultural. The semantic quarantine, with its taboos and labyrinthine structure, is a testament to their discursive efforts to achieve an undetectable “stigma load.”
CHAPTER 7: COMMODITIES, CITIZENS, AND CLIENTS

Introduction

This chapter addresses the third research question explored in the dissertation, which asks whether the heterosexual HIV-serodiscordant couples in this sample conceive of risk and/or HIV itself as an opportunity (Zaloom 2004) or a commodity (Crane et al. 2002; Abadía-Barrero 2002; Leclerc-Madllala 2006) that can be exchanged for goods, services, or social inclusion/status. More specifically, it considers to what extent they can be seen as engaging in what has variously been called biological or patient-citizenship on the basis of HIV/AIDS (Petryna 2002; Biehl 2007). As described in the Chapter 1, commodification and patient-citizenship were integral to the formulation of this research, in that the conceptions of risk undergirding these two phenomena provided concrete alternatives to biomedical paradigms that construe risk as inherently undesirable. Further, the work of João Biehl in particular, for reasons of common geographic context and theoretical affinity, often served as an implicit interlocutor in the analysis of the data reported here.

Before proceeding to this analysis, however, a brief review of the relevant literature is necessary. Therefore, in the first section, I reiterate key details from the literature on commodification, and then examine various approaches to biomedically-mediated citizenship (hereafter abbreviated as BMMC). In addition, an alternative concept proposed as an explanatory framework for the “claims-staking” behavior of seropositive people, “clientship,” is discussed. In the second section, points of particular relevance from this literature for this project are highlighted, and employed in the development of criteria used to decide whether
opportunism, commodification, and/or citizenship practices can be indentified in the collected data. Only then, in the third section, are the data analyzed, largely through the lens of three general trends that characterize the actions of the sample as a whole. In the fourth section, data from one seropositive participant who represents a marked deviation from these trends are presented as a case study. Finally, the conclusions that can be drawn from these findings are explored.

**Commodification and BMMC in Review**

As outlined in the discussion in Chapter 3, a small but important body of work exists that views risk for HIV, and the virus itself, through the prism of commodification. Based on the statements and actions of research participants, these treatments recognize that the meanings attached to HIV are sometimes—in clear opposition to hegemonic, biomedical conceptions—positive. As a result, individuals either actively pursue, or neglect to prevent HIV transmission. Scholars have documented such dynamics among various groups, including bug chasers and givers; impoverished, HIV-positive individuals in California and South Africa; marginalized street youth in Brazil. Also noted in Chapter 3 was the existence of a slightly different literature, united by its recourse to notions of citizenship. That literature is explored more fully in this section.  

To summarize what was reported previously, however, seminal works on various forms of BMMC do not address ways their theories may relate to work on commodification (e.g., Crane et al. 2002; Abadía-Barrero 2002; Leclerc-Madlala 2006). It may be argued that in any

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101 There are many recent scholarly examinations of citizenship. Some are wide-ranging and highly influential (e.g., Isin and Turner 2002); some are specifically anthropological (e.g., Rosaldo 1994; Ong 1996; Holston 2008), even focusing on the way notions of citizenship or nationality impact access to health care (e.g. Ong 1995; Whiteford and Branch 2008; Goldade 2011; Murray et al. 2011), or ideas about “deservingness” (e.g. any of the articles in the recent special edition of Social Science & Medicine, see Sargent 2012). This review is much more narrowly focused on work framed by a particular understanding of biopolitics, the authors of which are in academic dialogue with one another.
attempt to obtain goods, services, or social inclusion through serostatus, HIV has already, to some extent, been commodified. This results, however, in foregrounding the actions taken by seropositive people, without necessarily considering what those actions mean to them. Again restating an argument made previously, “claiming a right” may be a qualitatively different experience than deploying HIV/AIDS as a medium of exchange. Casting this now in Gee’s (2005) terms, these actions may draw on different Discourses and Conversations, and hence, may involve distinct “who-doing-whats.” It seems best, in the absence of data that justify treating commodification and BMMC as synonymous, to remain open to the possibility that they could be meaningfully different—and, further, that they may not be the only options available.

BMMC: Seminal Literature

Turning now to notions of citizenship, the analysis presented in the previous chapter drew heavily on dichotomous citizen/non-citizen identities to explain the risk-related discourse of HIV-serodiscordant couples. While this iteration of citizenship does not exactly fit within the parameters of this review, it does connect with the work to be discussed, and so presents a convenient and familiar place to begin. To reiterate Briggs and Mantini-Briggs’s idea, sanitary citizens “possess modern medical understandings of the body, health, and illness, practice hygiene, and depend on doctors and nurses when they are sick” (2003:10). Those who fail to meet the above criteria, or who refuse to abide by them, are deemed unsanitary subjects. Being classified as an unsanitary subject brings with it stigma, but also “medical profiling,” or “differences in the distribution of medical services and the way individuals are treated based on race, class, gender, or sexuality” (Briggs and Mantini-Briggs 2003:10). In medical profiling,
cultural practices are often reified and seen as indexing unsanitary subjectionhood, which is then blamed for ill health.

A similar dynamic was implicated in the difficulty accessing treatment—or even being diagnosed—encountered by the homeless, HIV-positive individuals in Biehl’s (2004a, 2005b, 2007) work. The profoundly marginalized frequently struggled to receive medical attention amidst the scarcities of the national health system, suffering from what the author (Biehl 2007:223) called “medical invisibility.” Diagnosed late, often in the grip of advanced AIDS, there was no continuity of care for these unsanitary subjects, who often left only one trace in public health records—the hospitalization that preceded their death. This was the result of “tacit norms of intervention” (Biehl 2007:224) that structure an unofficial triage. Applying Briggs and Mantini-Briggs’s terminology, to pass through this initial filtering process, individuals must be judged sanitary citizens. According to an early description by Biehl (2004a:120), the triage is stringent: “Specialized health care is provided to those who dare to identify themselves as AIDS cases in an early stage of infection at a public institution and who autonomously search (they literally have to fight for their place in the overcrowded services) for continuous treatment.” These lucky few (who clearly fit within the broader category of sanitary citizens) are termed “patient-citizens” by Biehl (2007:224).

While Biehl’s concept articulates with that of Briggs and Mantini-Briggs, their work resides in separate academic “villages.” What I mean by this is that they are not in conversation with each other, largely due to an important difference in their focus. Briggs and Mantini-Briggs brilliantly elucidate how would-be patients are recognized—in terms of Gee’s (2005:23) notion of a “who-doing-what”—by biomedical professionals, and the authors lend voice to the very different interpretations of selves and events offered by those suffering from disease. Biehl also
considers how the perspectives of authority figures shape who receives care and who does not, and the way some patients frame and produce their own experience. The difference is that many of the patients in Biehl’s work adopt and adapt hegemonic discourse about HIV/AIDS to their own ends. Note how, in Biehl’s definition above, behavior and self-concept are both important and concordant: seropositivity is a significant and foregrounded component of identity that—at least as revealed to him, and articulated to biomedical professionals by those he studied—structures particular practices, including acceptance of and adherence to ARV treatment. This combination is what translates to a “mode of claiming citizenship for the previously disenfranchised” (Biehl 2007:121) within a national context where health is constructed as a human right and achieved through “the emergence of a new political economy of pharmaceuticals” (Biehl 2004a:123).

Biehl’s knowledge of the particular ways that “marginal” groups make use of these “new fields of exchange and possibility” (Biehl 2005b:252) is based on his work with the residents at a particular AIDS NGO, which he calls Caasah, in the state of Bahia. He asserts (Biehl 2004a:123) that the process he saw at work there differs from the dynamic typically featured in treatments of social inequality in Brazil, because, at Caasah:

> the diseased biology of these abandoned is not simply an embodiment of marginalization and exclusion to be policed; it is also a technical means of inclusion. While these people learn new scientific knowledge and navigate through new laboratories and treatment regimes, they constitute themselves as [patient] citizens and force an inclusion into a sophisticated form of pharmaceutical control.

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103 In Portuguese, as mentioned in the Chapter 2, this word cannot be divested of its connotation of poverty and criminality.

104 At this point in the development of his ideas, Biehl had termed these people “biomedical citizens;” I have altered the terminology to accord with his later, more developed understandings so as not to confuse the reader.
While this inclusion is limited, selective, it is also, he argues, unprecedented. Among the many goals of Biehl’s research is to “reveal the extent to which people in the margins learn to use medicine and technology to enhance their claims for social equity and human/biological rights” (Biehl 2004a:124).

As previously noted, “patient-citizenship” is akin to Adriana Petryna’s (2002) “biological citizenship” in that both concepts extend Rabinow’s (1999) “biosociality” into new ethnographic territory. Transposing Rabinow’s idea into the terminology employed in this dissertation’s discourse analysis, he says essentially that new diagnostic technologies engender novel identities—new “whos”—with potentially significant consequences. In Petryna’s work these “whos” are poterpili, or “sufferers,” defined by their exposure to harmful levels of radiation in the Chernobyl disaster of 1986 (Petryna 2002:4). The post-socialist Ukrainian state was legitimated in part through its response, including financial assistance, to this biologically-identified group. Life Exposed (Petryna 2002) documents the politics and practices of measuring and assigning meaning to radiation exposure, as well as the efforts of individual poterpili to win compensation from the state, an endeavor Petryna characterizes as “biological citizenship.”

This is also the term employed by Rose and Novas (2004:440) to “encompass all those citizenship projects that have linked their conceptions of citizens to beliefs about the biological existence of human beings, as individuals, as families and lineages, as communities, as population and races, and as a species.” Their contribution to this literature is theoretical rather than ethnographic, but no less important for that. Given the definition they offer, it is not surprising that they understand biological citizenship as having a long history. However, they see the social organization springing from biological classifications as “increasingly significant,” and distinguish several different forms the practice can assume. Specifically, they term
“specialized scientific and medical knowledge of one’s condition” as “informational bio-citizenship,” while “the usual forms of activism such as campaigning for better treatment, ending stigma, gaining access to services, and the like” are called “rights bio-citizenship.” Finally, they see “incorporation into communities linked electronically by e-mail lists and websites” as a new form: “digital bio-citizenship” (Rose and Novas 2004:442). The other work reviewed in this section does not employ a comparably-detailed breakdown of particular forms of BMMC, but these diverse practices are in evidence across the body of literature as a whole.

Another point made by Rose and Novas that is echoed across much of the work surveyed here is that these forms of bio-citizenship, in certain contexts, come to constitute ways that populations are disciplined, in the Foucaultian sense: “The enactment of such responsible behaviors has become routine and expected, built in to public health measures, producing new types of problematic persons – those who refuse to identify themselves with this responsible community of biological citizens” (Rose and Novas 2004:451).

V. K. Nguyen (2004:132), writing in the same volume as Rose and Novas, is also interested in illustrating “how techniques for managing populations and bodies produce particular kinds of subjectivities.” Writing based on experiences in Burkina Faso and Cote d’Ivoire, he, along the same lines employed by Biehl, describes the connections between patented ARVs; actions taken both by groups within developing countries and by the governments of those nations on the international stage; drug prices; and HIV treatment on the ground. He also accords special consideration to the process and form of humanitarian interventions around HIV/AIDS. This confluence produces what Nguyen (2004:142) terms “therapeutic citizenship—a form of stateless citizenship whereby claims are made on a global order on the basis of one’s biomedical condition, and responsibilities worked out in the context
of local moral economies” (for more on therapeutic citizenship, see also Nguyen 2010; Nguyen et al. 2007)

Finally, another variant of citizenship that is heavily cited within this rapidly-growing body of literature comes from Robins’s (2004) study of the Treatment Action Campaign (TAC) in South Africa. More an organizational ethnography of TAC than an exploration of what he calls “health citizenship” per se, it nonetheless provides an account of the conditions under which some members, and especially the leadership, of TAC developed subjectivities that included notions of “rights.” Particularly notable is his recognition that the health citizenship TAC promotes includes ideas that may conflict with traditional notions regarding autonomy and sexuality, especially for women (Robins 2004:667); in general, the other work considered thus far does not foreground analysis of gender.

But this is just one example of a more general observation that deserves mention: Robins points out that TAC is composed of (at least) two dimensions that—sometimes uneasily—co-exist. While TAC is “a rights-based social movement that uses the courts and constitutional rights to health care, it is also a grassroots social movement” (Robins 2004:668). To him, this means that official pronouncements and actions of the group, which propagate biomedical orthodoxy about HIV/AIDS and advocate for the extension to and uptake of the latest standard of care by all seropositive people, while powerful, are not monolithic. Specifically, many participants “appear to have accepted the biomedical truths and rights-based approaches to health citizenship … [but] this does not necessarily exclude beliefs in the occult or other faith-based and spiritual forms of healing. ‘Conversion’ to ‘mainstream’ AIDS science may be partial and precarious” (Robins 2004:668).
The work covered thus far (with the exception of Briggs and Mantini-Briggs’s monograph) appears—by virtue of the frequency of its subsequent citation—to constitute a starting point of sorts, in terms of what Whyte (2009:6) sees as one of two main perspectives though which social scientists are currently conceptualizing “the way power shapes sense of self and other.” In contrast to treatments that adopt the lens of identity politics, she argues that, in these “biopower approaches,” social actors are not necessarily cognizant of the processes impacting them, and that the perspective taken by authors “problematicizes the workings of discourse and technology in the shaping of subjectivity and new kinds of social relations” (Whyte 2009:13). This is a fundamental characteristic these seminal works share, along with many of the scholarly pieces written in dialog with them (e.g., Fitzgerald 2008; Cataldo 2008; Meinert et al. 2009; Beckmann and Bujra 2010; Colvin et al. 2010; Fraser 2010; Kielmann and Cataldo 2010; Greenhough 2011; Mfecane 2011; Richey 2011, 2012; De la Dehesa and Mukherjea 2012). In the context of this chapter, however, there are a few, relatively more prosaic, details I wish to highlight before moving forward.

Despite the tendency to treat the various forms of BMMC as equivalent (e.g., Cataldo 2008; Beckmann and Bujra 2010; Kielmann and Cataldo 2010), there are important differences between them. First and most obviously is the context from which the concepts were developed. Both Nguyen and Robins, for example, were writing from geographic, historical, and organizational contexts characterized by a political struggle over whether to provide access to ARV treatment. Moreover, their work was conducted from within NGOs, or with prominent individual activists, heavily involved in this struggle. It is, therefore, an open question whether the forms of citizenship they identify would manifest under other conditions, and whether they can also be found among people who did not engage in an equivalent degree of activism.
Indeed, despite Robins’s (2004) acknowledgement of the “dual” nature of the TAC, there is little ethnographic documentation of links between the organization’s actions and (non-leader) members’ personal beliefs and identities. Likewise, Nguyen’s (2004) focus, in his most frequently cited paper, is on the leader of a support group in Burkina Faso and a seropositive, French doctor who operates a clinic and research center in Cote d’Ivoire. Their attitudes and actions are treated as emblematic of the groups they (ostensibly) represent—but with little data presented to support this conflation of organizational and personal expressions of citizenship. To some extent, this may be an artifact of focusing on the dynamics of collectivities, rather than the experience of individuals—by no means inherently problematic within the frame of individual publications.

Nonetheless, this analytical architecture should not be overlooked when attempting to apply insights from such work to other contexts. Inadequate attention to these factors can lead to imprecise appropriations. For example, Kielmann and Cataldo (2010:24) define “patient citizenship” as “patients’ awareness of rights, motivation and agency to act on behalf not only of their own health, but also on behalf of collective interests in HIV prevention and care.” Since Biehl’s oeuvre is the only “foundational” basis of this literature to employ the term “patient-citizen,” we must assume that Kielmann and Cataldo intend their statement to invoke his ideas. But acting “on behalf of collective interests in HIV prevention and care” is only an implicit component (if that) in Biehl’s definition of patient citizenship (see above). Emphasis on collectivities—particularly trans- or international ones—derives from work more in line with “health” or “therapeutic” citizenship.

Here again, context and analytical priorities beg consideration. Biehl’s work is no less specifically “situated” than Robins’s and Nguyen’s—but it is differently situated. First, during
much of the period encompassing Biehl’s field research, legal guarantees to ARV treatment were already a reality in Brazil. What was being contested was the inclusiveness of, and the logistics through which, this guarantee would operate in practice. Second, although parts of his ethnographic research were carried out at an NGO (one that specialized in treating marginalized AIDS patients), and the processes characteristic of that social space are portrayed as integral to the identity development of those who passed through, Biehl’s primary focus is not on Caasah as a political actor. Instead, to the extent the ethnography addresses the lived experience of seropositive people, it is concerned with the way individual residents adopted (or did not) biomedical orthodoxy about HIV/AIDS with the intention of securing care and achieving a degree of social inclusion for themselves that had been previously out of reach. Once more, this focus is neither “good” nor “bad” in and of itself—it simply is. But other scholars must be cognizant of the structure that shaped theoretical concepts they are interested in exploring in their own work.

Thus far, one issue confronted in this literature is an inadequate, or perhaps merely scantily supported, differentiation of the actions taken in pursuit of “citizenship” by collectives and individuals. Phrased somewhat differently, we might say that members of collectivities are presumed to behave in ways that mirror the actions of the larger organization. This occurs more frequently in work that, like Robins’s and Nguyen’s, is conducted from an NGO or other civil society context. A second issue is more likely to be encountered in research that, like Biehl and Petryna’s, begins from therapeutic locales. What sometimes receives short analytical shrift here is that actions taken by individuals in pursuit of benefits or rights associated with citizenship are presumed to stem from a subjective sense of entitlement to those benefits—that is, from a

105 And analogous conditions pertained in Petryna’s work with poterpili: the governmental commitment to providing support already existed, but criteria determining eligibility for this support were actively being negotiated.
construction of the self *qua* citizen (e.g., Cataldo 2008:906; De la Dehesa and Mukherjea 2012:190; Loewenson 2007; Watson and Stratford 2008). But whether the identities a “citizen” label denotes truly motivate behavior, or the degree to which they do so under various circumstances, should be an object of empirical verification. Paraphrasing Susan Whyte, (2009:9) “Ethnography does not assume [identity] but questions the conditions for its existence.”

**Critiques of BMMC: Focus on Clientship**

Happily, just such a preoccupation appears to animate a growing number of publications that problematize theories of BMMC. This is usually done through a close comparison of theoretical precept to ethnographic detail. For example, Colvin et al. (2010), Mfecane (2011) and Richey (2011) suggest that an awareness of the different constraints and opportunities posed by masculinity and femininity complicates our understanding of who can aspire to these forms of citizenship, and what they must do to achieve that goal. Perhaps even more fundamentally, based on work on South Africa and Brazil, Kielmann and Cataldo (2010:25) exhort scholars to avoid “the assumption that patient identity is a given, to the point of eclipsing other dimensions of personhood. A basic, but neglected consideration is that many individuals may simply choose not to forefront HIV as the central or defining issue in their lives.” The implicit corollary is that if seropositive individuals do not primarily or even consistently think of themselves as “patients,” the likelihood of their identification as a “patient-citizen” is also called into question.

Other researchers do more than just urge caution; they suggest alternative explanations. Of particular interest, given Brazil’s history of political stability achieved through patron-client relations (Boaventura de Sousa Santos 1998; Skidmore 1999; Bethell 2000; Voss 2002; Holston 2008), is the recent emergence of a group of articles employing the notion of therapeutic “clientship” (Meinert et al. 2009; Beckmann and Bujra 2010; Mfecane 2011; Richey 2012). The
field research on which these analyses are based was conducted in Uganda, South Africa, and Tanzania,\footnote{But see Collins 2008 for a slightly different application of clientelism to AIDS in Northeast Brazil.} which, while presenting differences in terms of HIV prevalence, governmental (and international) responses to the epidemic, and levels of stigma, are all—according to the authors—places “where politics in general is based in patron–client mode” (Beckman and Bujra 2010:1057). They are also places where, because of stigma, the relative newness of HIV treatment, the lack of an “AIDS movement,” or poverty, traditional forms of sociality—namely, friendship, kinship, and clientship—are understood as more dominant than health-centered identities (Mfecane 2011:195; Beckman and Bujra 2010:1041; Richey 2012:829).

In these contexts, much as was reported by Leclerc-Madlala (2006) and Boesten (2011), in the wake of access to ARV treatment, seropositive people’s primary concern may have “shifted from physical survival in the face of fatal illness to economic survival and reintegration into society. Anti-retroviral treatment allows people to hide their HIV status and avoid stigmatization. This facilitates their new quest for work, partners and a ‘normal life’” (Beckman and Bujra 2010:1056). Returning to “normal life” may entail returning to “normal” ways of relating to others. Thus, as Richey (2012:829) points out, seropositive participants in her research negotiate multiple, context-dependent identities, which do not necessarily mesh well with BMMC. Meinert et al. (2009:205) agree: “The sociality of being a client … involves respecting the programme, being ‘docile’, and grateful in a way that seems different from the more politically active, rights-focused, sociality that the notion of therapeutic citizenship suggests.”

The importance of accurately distinguishing between citizenship and clientship in the context of HIV/AIDS treatment lies both in the individual impact these different relationships might have, in, for example, patient-doctor interactions, and in the wider effect on society of the
exercise of such divergent socialities. In clientship, deference and loyalty are owed by the less powerful to the more powerful entity; these are the conditions on which access to a share of the more powerful actor’s resources is predicated. Access to those resources is what makes this structural inequality acceptable from the less-powerful actor’s point of view (Voss 2002; Fox 1994). Neither party to this interaction need be deliberately perpetuating this dynamic—as part of a cultural model for interactions between people of differing social status, it is precisely the kind of cultural knowledge likely to be tacit. As is clear, however, clientship is transactional, built on an underlying ideal of exchange, which means it has potentially more in common with the commodification approaches detailed in Chapter 3 than it does with notions of citizenship, which, as exemplified through multiple citations in this section, is built on underlying concepts of rights.

What the authors cited above are arguing, in essence, is that poor clients see clinic personnel as patrons who provide access to ARVs and medical treatment. It is consequently important to retain their favor by at least presenting the appearance of “loyalty”—in this situation, adherence to treatment. Whether they can and do in fact adhere to treatment has consequences for the individual’s health, as well as his/her infectiousness to others. But on a larger scale, more fundamental issues are at stake. It matters whether new models for relationships (citizenship) are coming into being, or whether old ones (clientship) are being adapted, altering but at the same time strengthening the status quo. As Richey (2012:842) explains, with reference to the therapeutic clientship she observed in South Africa and Uganda:

It is no surprise, therefore, that patronage is the preferred mechanism for actually getting the ARVs from the therapeutic regime. It is the one that works. In the process, no expansion is made in terms of claiming rights on the basis of equal human worth, or the old liberal notions of what rights citizens hold on the basis of their belonging to a specific territory. The provision of AIDS treatment in Africa therefore looks strikingly less like building new forms of global citizenship, and more like the
traditional forms of vertical development aid, built not on rights, but on discretion.

Summary and Discussion of Relevant Literature

To summarize, then, a growing and influential body of literature sees the achievement of access to life-saving ARVs by certain populations as indicative of new forms of citizenship. By “citizenship” these authors seem to focus on perception and actions on the part of the state, which entail the recognition of an individual as a legitimate member of the body politic, and the extension of rights and services thereby due him or her. This particular kind of who-doing-what, that is, a “responsible” patient who deserves social inclusion, has been documented in various ethnographic contexts. However, it occurs as a social type under two basic conditions. First, politically, it requires an interlocutor conversant in BMMC Discourses to “recognize” the “citizen” identity-action composite. In places where ARV treatment is a national responsibility and fairly well-established (like Brazil), that interlocutor will likely be some type of representative of the state.107 It is for this reason that BMMC theorists frequently couch their analyses in terms of “rights;” would-be citizens stake claims in the hope of holding state actors to their own lofty rhetoric (as exemplified by Brazil’s discourse and action on health as a right, as described in Chapter 2). The second condition that characterizes BMMC practices is rooted in economics: those attempting to be recognized as “citizens” are either anxious about losing social status (as in the case of the poterpili Petryna worked with), or have—because of poverty or other suggestions of marginality—been largely invisible to the state as a matter of course (all other groups studied by scholars whose work is considered in this section fall into this category). Thus, for both conditions, context is of consummate importance.

107 In places where treatment is not available or available only through non-state actors, that interlocutor is likely to be international in character—hence, Nguyen’s assertion that therapeutic citizenship is “stateless.”
A nascent line of critique, however, offers a different, or additional, analysis. Instead of “new” citizenship-based modes of relating to the state (or international community), these scholars see continuity, in the form of patron-client relations (or at least the incomplete dissolution of clientship by citizenship dynamics), as shaping access to HIV treatment. Thus, their discussions center not around “rights” and equality, but around favors, personal relationships, and inequality. No less than in the citizenship analyses, however, are patients required to perform as recognizable who-doing-whats; what may differ are the criteria by which that performance is judged. It is also notable that, because of the understood power differential in patron-client relationships, many of the same groups that receive analytical attention from citizenship theorists—the poor, marginalized, and others who feel vulnerable—are the focus of clientship perspectives. Thus, both patient-citizens and clients engage in these interactions because they have little to lose, and potentially much to gain.

Another commonality between these approaches is a not-always explicit two-dimensional, and dialogical quality. What I mean by “two-dimensional” is that both the patient/client’s self-recognition as a particular kind of person, and the actions taken in the world on the basis of this identity are implicated. Patient or biological citizens frame or understand their experiences or selves in terms congruent with biomedical understandings of their condition; clients do so in terms reflective of their social position. These identities produce claims-staking behaviors of particular types. For patient citizens, biosocial evidence is needed to substantiate claims to benefits or rights; accordingly, individuals have to qualify biologically or immunologically, as well as meeting social and moral standards that include renouncing unacceptable identities and habits, acquiring scientific or institutional knowledge about the disease and the health care system, and engaging in (documented) proper forms of self-care.
These same behaviors may be required of clients, though the rationale for engaging in them—to curry favor with or demonstrate loyalty to the patron—is different. The dialogical quality of these interactions derives from the fact that, in both citizenship and clientship perspectives, the state or patron must recognize (or not) the performing individuals as fulfilling certain necessary biosocial criteria, and compensate them accordingly. As should be clear by now, and echoing the earlier argument made more generally about commodification and BMMC, in both cases, the very same empirically-observable actions on the part of a physician and a seropositive person (prescribing ARVs and providing ongoing care, and adhering to the medication regimen and avoiding “irresponsible” sexual behavior, for example) can figure in practices of citizenship and clientship. The difference lies in the subjectivities involved.

**Notes on the Sample and Operationalizing Theoretical Concepts**

Two observations must be made about the way the sample of HIV-serodiscordant couples in this research differs from the participants in the majority of studies in the foregoing review. As stated above, whether considering the category of commodification, citizenship, or clientship, the patients populating that work were frequently extremely impoverished. Although I attempted to recruit couples experiencing an analogous degree of marginalization (see Chapter 4), that simply was not feasible. None of the couples in this sample were homeless; most had a steady, if meager, income. In fact, half of them classify themselves as “middle” or “lower-middle” class. To the degree that commodification, citizenship practices, or clientship strategies are more likely to be employed by those with little to lose in the way of economic capital, this sample may not be the most propitious for observing such dynamics at work. It may, however, be instructive in terms of identifying a type of class-based or economic “ceiling” above which the frequency of the approaches to life with HIV diminishes.
The second way my sample differs from most of the others is in their relative lack of experience with NGOs or AIDS-related civil society. In treatments like Robins’s (2004), Nguyen’s (2004), and Biehl’s (2007), the forging of citizen identities was attributed at least partially to the crucible of the collective struggle to achieve conditions of survival in the context of AIDS. Even where access to treatment was relatively secure (e.g., Leclerc-Madlala 2006; Cataldo 2008; Mfecane 2011; Beckman and Bujra 2010; Colvin et al. 2010; De la Dehesa and Mukherjea 2012) participation in support or informational groups provided a key venue for the development of patient identities that could be mobilized to press for common demands. When I asked my participants if they could name AIDS-related civil society groups (ONGs Aids), none of them could—although two of them said they had visited webpages or chat groups about living with AIDS. In Rose and Novas’s terms (2004:442), there was little digital bio-citizenship occurring and virtually no rights bio-citizenship.

Given the diversity of contexts in which commodification, BMMC, and clientship were portrayed in the literature, as well as the ways my couples diverged from what seemed a relatively homogeneous make-up among other scholars’ samples, I needed a way to answer the question, “If such phenomena were transpiring, how would we know?” Therefore, after reviewing the relevant literature, I developed criteria for assessing my data, based on what I considered the consensus among most scholars about necessary characteristics and conditions. These criteria are reviewed below.

**Analytical Criteria**

Although it has fallen a bit to the wayside in this discussion, one of the primary dynamics I was interested in, based on anecdotal evidence I encountered among biomedical professionals at the clinic, the application of Zaloom’s (2004) reasoning to HIV/AIDS, and Leclerc-Madlala’s
(2006) findings in South Africa, was the construction of risk as an opportunity. Also extrapolating from Moskowitz and Roloff’s (2007) work, I believed that actions motivated by this construction might fall along a continuum. Indications were expected to range from seronegative individuals’ active pursuit of HIV infection and discussion of this eventuality in positive terms, to more ambivalent expressions, such as making little or no attempt to avoid transmission, suggestions that HIV is “no big deal,” and explicit connection of seroconversion with particular benefits. This was seen as an “extreme” manifestation of the commodification of positive HIV serostatus, in that the construction of risk as opportunity indicates the allure of the exchange is sufficient to actually motivate infection-seeking behavior.

As stated in the section above, in virtually all the scholarly production on commodification and forms of BMMC, there figured both a process of identity creation and discrete acts undertaken with the purpose of accessing desired goods, services, or social inclusion. This chapter attempts to address both aspects, although more emphasis is accorded the discrete acts, due to their greater accessibility to the researcher.

In order to argue that either commodification/clientship or BMMC are present in the data, it seems to me, based on the literature surveyed above, four prerequisites be considered.

1) Seropositive individuals must be aware of goods, services or status that can theoretically be obtained through an HIV or AIDS diagnosis.

2) They must try to access those benefits. Scholars may debate whether the level of detail or veracity of such knowledge, or the means by which it is acquired, are considered important, but individuals surely cannot be seen to “stake claims” if they are unaware that something is available to be claimed. Hence, knowledge and action are important.
3) In pursuing those benefits, patients must present themselves (at least in those pertinent situations) in terms of a biological or medical condition recognized by the state as potentially legitimating the claims they stake, in this case, having HIV or AIDS.

4) Finally, if we wish to distinguish between commodification/clientship and BMMC, it must be possible to justify the assertion that attempts to access HIV-related rights and benefits constitute new forms of citizenship, a claim made by Petryna (2002), Robins (2004), Nguyen (2004, 2010; Nguyen et al. 2007), and Biehl (2007). Therefore, a necessary element of BMMC expressions is that petitioners conceive of the mediation of their claims as dependent on an ostensibly objective, juridical process, not a system of favors or personal relationships. This presentation may make use of a rights-based discourse, but such language is not strictly necessary. When patients exhibit self-presentations or articulate their experiences in biomedically-recognized ways but seem to favor personalistic motivations or explanations for the benefits they pursue and/or receive, this may, following Richey’s (2012) usage, signal an example of “therapeutic clientship.”

**Overview of Findings**

Through countless informal conversations with patients and practitioners in two different therapeutic contexts, and multiple encounters with members of serodiscordant couples outside of the clinic, I remained alert to constructions of risk, especially its possible commodification. However, I uncovered no concrete evidence of the conscious pursuit of HIV that academic literature and anecdotal evidence encountered in 2007 suggested might be present. I also never heard any patient, let alone a member of the couples with whom I had close working relationships, speak of seroconversion in positive terms. Further, although some research participants—especially those who did not consistently use condoms—implied HIV infection
was “no big deal,” the analysis offered in Chapter 6 complicates such assertions by uncovering a suite of linguistic strategies—the semantic quarantine—designed to insulate speakers and their partners from discursive association with stigmatized ideas and identities. In addition, these statements, ostensibly reflecting the banalization of HIV, were not connected to expected receipt of any kind of benefit. My data, therefore, provide no basis for claims that the participants in this research seek out HIV infection, or construe the risk thereof as an opportunity (Zaloom 2004).

This leaves open the possibility, however, that HIV infection, once acquired, might be commodified vis-à-vis the state—that is, mobilized by patients to procure publicly-provided goods, services, or social inclusion—or made the basis of practices of BMMC. Such a dynamic could be operant even within couples actively striving to prevent HIV transmission. I observed my small sample and listened to the way they framed events in their lives and the actions they had taken in response; I struggled to understand whether other scholars’ ideas were applicable in these cases. What I discovered was a range of practices, knowledge, and values around HIV, and health more generally, that seemed to suggest highly contingent actions, rather than consistent strategies. Key among my findings (F1-F3), though, were the following:

F1: On the whole, these serodiscordant couples were not well-acquainted with the rights conferred by an HIV/AIDS diagnosis.

F2: When seropositive members of these couples did solicit information or benefits through the clinic, it was as “AIDS patients” but usually in response to a specific need they were facing at the time.
Participants rarely employed a rights-based discourse about HIV. Significant variation existed in terms of the ways they appeared to conceptualize access to serostatus-based entitlements, but individual people and personal relationships were often foregrounded.

Overall, these findings do not support claims that seropositive research participants in this sample consistently identify and act as “patient-citizens.” There is, in my opinion, slightly more evidence to support clientelistic approaches to obtaining benefits, but this is also not an incontestably dominant mode of interaction.

The reader can readily identify these individual findings in the presentation of data below; however, the stories explored are complex, often articulating with more than one finding. This makes advancing a linear argument challenging. Instead, I have chosen to group data according to topic, with the relevance of major findings signaled throughout. I discuss, for example, participants’ statements on and experiences with several HIV/AIDS-related entitlements, their (non-)use of rights discourse, and their conception of how benefits may be obtained. Finally, I detail the case of one seropositive participant that provides a fairly dramatic contrast to the rest. While this produces a narrative thread that may feel somewhat circuitous, the form facilitates comparison and contrast, and preserves the rich character of participants’ lived experience. This is important because, ultimately, as Richey (2012) noted, the interpretation of this particular slice of health culture has implications that extend far beyond the lives of these particular couples. It speaks not only to conceptions of the doctor-patient relationship that influence the quality of care that can be provided, but also to the way certain members of Brazilian society perceive and interact with social institutions. These last points will be taken up in the final chapter of this dissertation. For now, we turn to the data.
HIV/AIDS-related Rights and Benefits

All couples in this sample were able to list some goods or services available to HIV-positive individuals by virtue of their serostatus. As stated Chapter 2, the word typically employed to refer to such things was *benefício*, which literally translates as “benefit.” Judging from the varied applications of this word (explored below), *benefícios* can be automatically granted, or they can be subject to approval via an application or petition process. Given this usage, it is plausible to suggest that they are considered a kind of “right.” However, at least half of participating members of couples seemed at times to conceptualize *benefícios* more in terms of favors extended by particular individuals to those in need, rather than “rights” *per se*.

When asked to list AIDS-related *benefícios*, participants mentioned free transportation on municipal buses; the opportunity for those involved in the formal labor market to “cash in” a government-mandated savings account called the *Fundo de Garantia por Tempo de Serviço*, or “FGTS”; and the possibility of obtaining temporary disability payments or a retirement pension. One participant also included having debts for housing (i.e., mortgages) forgiven. Of these benefits, no confirmation was ever found for the latter, and HIV/AIDS was not the only condition through which one could qualify for the former three (as participants usually explained). Before turning to serodiscordant couples’ statements on and experiences with obtaining these *benefícios*, however, a striking lacuna must be addressed.

**Treatment for HIV/AIDS**

Amazingly, when asked to list HIV/AIDS-related *benefícios*, participants never mentioned the one they all had the most direct experience with: medical treatment. In the course of other interactions, however, the unanimous awareness of government provision of ARVs, other needed medications, specialized care, and services designed to prevent vertical
transmission, became clear. This omission was surprising, given the struggle necessary to make universal and free HIV care a reality in Brazil (see Chapter 2), and the fact that at least one participant claimed that, without it, she could not envision serodiscordant intimate relationships as a possibility. Only Felipe, Bibiana’s seronegative husband, mentioned—albeit not as a benefício—Brazil’s landmark 1996 legislation that guaranteed access to ARV treatment. Otherwise, the provision of ARVs was generally treated as unremarkable (except in terms of shortages) or was not well understood, as the following examples indicate.

The availability of ARV treatment, for instance, seemed taken for granted by the three seronegative members of couples that did not consistently use condoms. Each minimized the gravity of potential seroconversion by referring to the effectiveness of these drug regimens. Adriano, several months after I met him, commented that he wanted to get another HIV test, “just to know if I have it or not. So I can feel calm or…feel calm too (laughs)! If I have it there’s nothing to do but start the treatment. If I don’t have it, cool.” When asked why he would undergo repeated testing if seroconversion made so little difference to him, he answered, “To get the medicine. If I have it, I’m going to start the treatment as soon as possible. So I can stay well, like [Rita], so we can have a long time together, living well.”

Milene likewise invoked treatment when reporting her attempts to calm Renato’s professed worry over her exposures to the virus: “Yeah, he’s going to feel guilty and things, no matter how much I tell him, ‘And if I get it? I’ll start treatment.’ I will, you know.” She claimed that her only worry about infection was that HIV might aggravate her other health issues; aside from such considerations, she said it was, “No problem! Because you know they have the medicine all worked out and everything.” Finally, despite Juliana’s assertion that she feared nothing, and that death would come independently of HIV serostatus, she also coupled
talk of potential seroconversion with medication: “If for some reason I have the bad luck to get [HIV], what is it that I’m going to do? Start the treatment. It’s the only way.” At least for these couples, the universal and free availability of ARVs in Brazil, which fewer than 15 years previously had catalyzed passionate debate in public health circles globally, had apparently become banal. Despite my “outsider” status and stated ignorance about the workings of the public health system, none of them ever talked about the “right” to treatment, or found it necessary to explain access to ARVs at all—they seemed to be treated like any other drug.

When that was not the case, however, confusion reigned. For example, Wílian, the model patient, expressed uncharacteristic confusion about this issue, saying: “At that time [I was diagnosed, the protocol] was: those who tested positive received treatment [i.e., started taking ARVs]. So since I started the treatment they could never stop giving it to me because… I don’t know why, but I think Brazilian law forbids that.” While Wílian trusts the continued availability of ARVs (probably as a result of his long experience as a patient in the clinic), any understanding of his “right” to them seems vague at best. In addition, although later in this same conversation he notes that treatment protocols have changed since he was diagnosed, he never addresses access to ARVs during the period prior to that point.

Bibiana also evinced a total lack of awareness of the history behind her access to the drugs she was taking. Talking about an acquaintance who was suffering from cancer, she noted, “I know the tests he has to do cost R$6,000 [out of pocket], ok? And so I get to thinking, how is it that I go [to the clinic]—I get the medicine for free, you know? Right? They’ve never been out; there’s been a little shortage, but nothing [serious]—you know? Never.” When I ask her what she would do if the clinic could not fill her prescriptions, she looked grave and replied:

Gosh, Shana! (pause) How desperate/scary, huh? Because if you depend on that and it’s not available [to buy], you know? I already checked…. You can’t buy these medicines. So I believe they won’t run
out. Because I think about it like this: Ok. If [the medicine] isn’t available for a month, you’re going to have to pay for your treatment for a while. And I think it’s worth it, but you have to have access. If you don’t have access, then it gets complicated. That scares me a little bit. I think if they don’t have it at the clinic, you should at least be able to buy it…. It’s not that I’m against the clinic giving medicine, ok? But I don’t really count on that because my whole life I’ve had to pay for things. Like [when I gave birth to] my daughter. I’m not used to going there and getting medicine for free, cash assistance, help with buying cooking gas. I’m used to working to have things. So I don’t count on that much and I think that whatever comes through is gravy. It’s like this: I’ve been taking meds for a year. If I have to pay for it for six months, and I have to work for that, sell a TV for that, I think I would do it, but I think that has to be possible, you know? You can’t not have the medicine through SUS and also not have it anywhere for sale.

Bibiana’s response makes two things clear. First, she does not understand the potential implications of making ARVs available for purchase (in terms of black market sales, adherence, and resistance), or how much such medicines would cost, were they for sale. Second, and most importantly for the purposes of this chapter, if she conceptualizes treatment for HIV (and, indeed, health care in general) as a “right,” it is only as an ideal, or in a relative sense. On a practical level, it is clear she does not—her statement to the contrary notwithstanding—feel confident that the ARVs she depends on will always be available through the public health system.

Further, this is not simply a case of acknowledging the divergence of ideal and real conditions, as other patients did when they said, “On paper, it’s a great system, but in practice…” (interview, 20 June 2007). Bibiana, in contrast, gives no indication that she feels entitled to treatment; she seems to expect to shoulder the financial responsibility for her medicines at some

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108 Here, Bibiana is referencing the fact that she gave birth to her daughter in a private hospital and paid for everything herself.
109 The cash assistance for families and cooking gas subsidy Bibiana mentions here are general government welfare programs; eligibility is not related to being HIV seropositive.
110 This may reflect a more general perception about the availability of medication. Research by Bertoldi et al. (2011) suggests that while a large percentage of medications needed by Brazil’s classe popular and poor are provided by the government, those groups still incur out-of-pocket expenses for some pharmaceuticals.
point. Unlike the patients who contrast the actual state of the health system with the way it should be, Bibiana’s ruminations on scarcity carry no undertone of deprivation or injustice; as such, it is difficult to view HIV treatment as a right she is claiming, rather than a windfall on which she thinks it unwise to rely.

In fact, very few of the seropositive members of the couples in this sample—or many of the other patients with whom I had more informal interactions at the clinic—gave the impression they felt their access to care was based on a right. Talk about “treatment” was not framed this way; rather, it frequently invoked personal qualities of particular biomedical practitioners, or the quality of relationship the patient had with them. Wílian, for example, extended a conversation about HIV/AIDS-related benefícios by focusing on clinic personnel:

> The attention they give there is very dear/high quality, good in every way, especially at that clinic where I go…They have support for patients they know are poor, that don’t have a way to get around, that can’t feed themselves…If the patient doesn’t have clothes, they do something about it. In the case of a mother, they give treatment for the pregnant woman and they give treatment for the child—everything.

While the clinic staff I observed was certainly dedicated, and some of them had related stories of personally obtaining particular items patients needed, Wílian’s framing reveals the extent to which he ascribes available assistance to the agency of individual practitioners, being either unaware of or uninterested in the state’s role. His lack of awareness that much of the assistance he lists is actually guaranteed to seropositive patients by law, coupled with his emphasis on individuals rather than the government, are significant deterrents to interpreting Wílian as a patient-citizen.

When questioned about the treatment they receive, most clinic patients talked about their physicians. Doctors’ reputations were largely consistent across patient reports. The most well-known and beloved physician at the clinic (and, to all indications, city-wide), for example, was
universally praised for his cutting-edge, specialized knowledge and compassionate manner, particularly his habit of physically examining his patients, even those who claimed to be experiencing no symptoms. Others were characterized as “a good doctor, but always late,” and “the sweet, little one,” among other, more potentially identifying monikers. In general, patients remarked that they “liked” their physicians. Yet, even when patients were displeased (for example, when they had scheduled an 8am appointment, and at 9:30 they were still waiting for the doctor to arrive), I never saw any of them do more than grumble to themselves and fellow patients who happened to be seated in close proximity. It seemed that care had to be taken (on the patient’s part) to maintain a harmonious doctor-patient relationship.

Renato was no exception. In lauding the treatment he receives as a patient at the clinic, he focused on how quick his check-ups were, and the pleasant conversations he and his physician had. I asked him if they had discussed the fact Renato’s partner was seronegative. He looked sheepish as he replied:

Renato: He doesn’t know.
Shana: He doesn’t.
Renato: No.
Shana: And what do you think he would say, if he knew?
Renato: He would insult/yell at me.
Shana: Really?!?
Renato: I think so (Shana laughs), in relation to our not using condoms.
Shana: But would you admit/tell that to him?
Renato: Well. That would be…ehhhh (makes a hesitant noise)...It’s like that. That’s why...It’s like I told you. We showed our cards (lit. “opened the game”) to you.
Shana: Right.
Renato: To other people, we don’t say that...We say we use [condoms].
I learned later just how important this omission was to Renato. I was at the clinic on the day of one of his subsequent appointments, and he invited me to observe. After his name was called, I stood up to follow him into the consultation room. Just prior to reaching the door, however, he turned around, eyes wide and urgent, and whispered not to tell his physician that he and Milene did not use condoms. I assured him I would not, but I was struck by the force of his anxiety and, by extension, the meaning he must have assigned to the doctor-patient relationship that generated such a powerful reaction. It did not suggest a relationship between equals.

In summary then, despite the pride of place awarded to “aid and treatment, given without any restriction” in the “Fundamental Rights” guaranteed to seropositive people,¹¹¹ none of the participants of this study mentioned medical care in their listing of HIV/AIDS-related benefícios. While approximately half of the sample seemed to take ARVs especially for granted (given the history behind Brazil’s commitment to making them available), other participants expressed confused understandings of the basis or logistics of this provision. No participant ever spoke of the “right” to health, or access to the public health system. In addition, other aspects of treatment or services provided at the clinic were also not definitively conceptualized as a “right.” Personal characteristics or relationships, on the other hand, cropped up frequently in patients’ discourse as explanations for assistance and quality care. Given the small size of the sample in this research, no attempt at gauging the generalizeability of such findings can be made. However, with reference to both awareness of benefits, and understandings of the processes for obtaining them, the data reported in this section suggest that, even when patients secure the medical treatment to which they are “entitled,” claims that they are exercising their “rights” as seropositive people

¹¹¹ As mentioned in the Setting chapter; full text of this document can be found online: http://www.aids.gov.br/pagina/direitos-fundamentais, accessed 19 January 2013
should be closely considered. Similar caution is warranted even when dealing with the benefícios participants did include in their lists, as will be seen in the subsequent sections.

The “TRI”

The most frequently cited example of a benefício was free transportation for AIDS patients on municipal bus lines. As described in Chapter 2, the purpose of this benefit is to reduce barriers to accessing HIV treatment. While the concession of free in-city transportation is surely essential to some AIDS patients’ ability to access care, few of the seropositive participants in this study required this subsidy. Xavier was exempt from paying bus fare because he was officially retired due to disability; he also had a motorcycle he rode when he was physically capable of doing so. Wilian and Bibiana had access to cars which they drove to and from work. Bibiana in fact joked about her TRI, and when I asked her specific questions about how it worked, she waved them off, saying, “I don’t know, Shana. I rarely use it. I never paid attention; I really never saw.” Although Renato and Rita had each had carteirinhas in the past (see Chapter 2), at the time of this research, both were formally employed and received a transportation allowance through their jobs.

This had also been part of Iara’s compensation package until she was fired; she did not apply for her TRI until then. As she told me, after being released from the hospital she had gone back to work, “so I had the transport card, those passes [employers] give you. I said, ‘No, I’m not going to do [the paperwork for the AIDS-based fare exemption]—it’s a lot of work…I don’t—I’m going to work, I don’t need that.’ Now that I stopped [working], I started everything.”

Eventually encouraged and assisted in this endeavor by a social worker at the clinic, Iara nonetheless encountered hurtful stigma as she attempted to obtain her TRI. In search of the
office that processes HIV/AIDS-based exemptions (which was not the same one that processes employer-provided TRI cards and credits), she asked a security guard for help. She related that he glanced at her paperwork, realized that her destination meant she was seropositive, and then exclaimed, “YOU??!” in disbelief and revulsion (Lara’s physique was not the skeletal frame still frequently associated with AIDS, so, barring circumstances like these, she was usually able to avoid such encounters). She continued the narrative, still clearly upset by what had happened: “He looked at me like, ‘Oh, how disgusting’…And to me, he already treated me differently, you know?” For Lara, then, exposing herself to HIV-related discrimination (which, as is evident in her couple sketch, she had believed was pervasive even prior to this incident), as well as the frustrations of dealing with the government bureaucracy, was only “worth it” once she was cut off from other sources of support.

One important observation regarding stigma and discrimination is warranted here: although no other participant reported personally experiencing such reactions in the course of informing themselves about or obtaining benefícios, every couple reported analogous encounters in other contexts, or fears thereof. The general perception of study participants was that, in order to access assistance to which seropositive people in Porto Alegre are entitled, they must be willing to face—from virtually any quarter—reactions that make it clear they are a less-than-welcome presence.

**Fundo de Garantia por Tempo de Serviço (FGTS)**

If the TRI was a well-known though little-accessed (by this sample) AIDS-related benefício, the Fundo de Garantia por Tempo de Serviço (FGTS) was less well-known and available on a more restricted basis (for a description of FGTS, see Chapter 2). FGTS was mentioned by only half of the couples in this sample (Rita, Adriano, Renato, Milene, and
Bibiana); this may have been because many of the participants would not have been eligible for this benefício. Wilian, Pamela, Xavier, Juliana, Iara, Jorge, and Milene, for instance, were not formally employed, so they had no FGTS account to be disbursed. Rita and Bibiana, having only recently obtained their positions, had very little accumulated.

To my knowledge, only Renato received an AIDS-based FGTS disbursement. A little over two months after I met him and Milene, they excitedly informed me about this upcoming financial windfall. Renato said he had heard of FGTS before but had not understood the details until a social worker at the clinic explained how the program worked. At the time they shared this news with me, they were waiting on Renato’s physician to return from vacation so he could sign the necessary paperwork. Milene, particularly, was relieved because, according to her calculations, the sum would be large enough to pay off almost all of the small debts the couple had incurred—with friends and family members, at the corner store, and on store credit cards—while she had been unable to work. The fact that Renato had been seropositive for so long without understanding his right to claim an FGTS disbursement suggests that, under certain conditions, lack of information can be a significant obstacle to patient citizenship. Having overcome this obstacle, however, Renato was able to negotiate the bureaucratic system that mediates such claims.

Programa Nascer

Other benefits and programs were far less frequently mentioned, and less well-understood, perhaps because they were relevant to only a very select sub-group of seropositive individuals. Programa Nascer, the Federal initiative known mostly for providing infant formula to HIV-positive mothers, is a good example (for a description, see Chapter 2). Although Milene, Jorge, Felipe, and Bibiana mentioned the possibility of preventing MTCT, more specific
information about these services featured in conversations with only two couples: Rita and Adriano and Wílian and Pamela.

Rita and Adriano were awaiting their first child during the period of this research. They had discussed their intention to start a family with Rita’s HIV physician, whose opinion was that nothing about Rita’s physical condition should prevent the couple from doing so. Rita’s first prenatal visit with the clinic gynecologist had gone well. Toward the end of our first formal interview, however, the following exchange occurred:

Rita: When I found out I was pregnant, I started thinking, “Oh, my God,” and I said to [Adriano], “Just imagine how much we’re going to spend on milk.” And he said, “What do you mean?” And I told him, “I can’t breastfeed; all my milk goes to waste, you know? The baby’s going to have to have milk—have formula.” I don’t know what kind it is, which one they’re going to say is best for the baby to have.

Shana: But you know the city provides the formula?

Rita: No, I know they do. I know…I knew that. The city provides it, right? I don’t know for how many months though.

In fact, Rita had not known that the city health department distributed formula to HIV-positive mothers (as of 2009, the ration was six cans a month, for six months) as part of the protocol to prevent vertical transmission. She admitted this during an individual interview several weeks later, saying, “Of course, I knew that the government gives the formula for the first six months, [but] only because you told me, you know?” Again, lack of information presents itself as an important obstacle to patient citizenship among this sample. Having yet to confirm the details of this program at the clinic, she remained worried about the potential expense. At a still-later interview, with both partners present, the issue came up again, with Rita commenting, “I have to talk to [the gynecologist] about the formula program. To see if they really have it.” Adriano told me this was very important to them; he seemed to count on my presence at the clinic, and relationships with the doctors, to help them obtain needed information,
saying to me “So, you know, right? Go and give [the gynecologist] a little push to get things all coordinated.” Rita added, “My appointment is on the 10th.”

This conversation, aside from demonstrating that the couple had not had the formula program explained to them, also highlights the personalized, rather than programmatic, way many participants in this research appeared to approach HIV-related benefícios. For them, benefits were associated with particular people who either would, or would not, provide access to others. At the time, I did not adequately appreciate how starkly this contrasted with my own conception of government assistance, which was based on the idea that following procedures and submitting required documentation made personal connections largely superfluous. As a consequence, my desire that the couple not be excluded led me to begin to explain the program procedures in detail. This appeared to confuse Adriano and Rita, who likely interpreted my attempt to impart information as a kind of renunciation of my obligation (resulting from our personal relationship) to make sure granting them access to formula became a priority for the gynecologist, who they conceptualized as being “in charge” of the program. I realized in retrospect that it was only when I mentioned the name and office location of the actual director of the program that the normal, friendly character of our conversation was restored—I had, in essence, shared my “connection” with them by signaling a person to whom they could appeal.

Wílian and Pamela spoke about Programa Nascer in strikingly similar—that is, personalistic—ways. They had needed this benefício when they adopted the youngest child of Wílian’s seropositive ex-wife. They also remarked upon the expense of formula, and implied that they never could have afforded it on their own:

Pamela: Yeah, it would have been difficult to buy that milk for [the boy], and Gabriela [one of the nurses] was like a sister and helped me a lot.

Wílian: Yeah.
Pamela: She really supported us, you know.

Wilian: And not just Gabriela but all the pediatric nurses.

*Programa Nascer*, as an intervention mandated and paid for by the Federal government, and administered by the municipality, is never recognized by the couple. Instead, they connect the formula they received to particular biomedical practitioners at the clinic, one of whom, because of the quality of assistance she provided, is described as being like family. Such talk seems a clear indication that the couple conceptualizes this benefit in terms that differ markedly from what one would expect if they were making the biosocially-justified claims that constitute patient citizenship.

**Disappearing Assistance**

Despite Wilian’s high praise for clinic personnel and the care they provided, he sometimes differentiated this from other types of material or financial assistance, and lamented that, despite the hardships his family faced, the latter was exceedingly difficult to obtain. His assertions fit in with a perception shared by some patients, long-time activists, and biomedical and public health professionals alike that, over time, HIV/AIDS-related benefits had been reduced, and it had become more difficult to qualify for them. As Wilian explained when I asked him about whether he received any *benefícios*:

> If it’s a person that has nothing, an extremely poor person, they give help, there are organizations. I believe that if I went to find out, they would help but they’ll need 50 different kinds of documentation and all, and if they come here and see the house we live in, they won’t give us anything. They only give to the miserably poor, the ones that live in little plywood shacks.... We don’t have a chance of getting anything, not even a food basket. It’s just for people who are on the street.

Rita also commented on nutritional assistance when I asked her if she were eligible for other benefits in addition to transportation and FGTS. She and Adriano, for example, had this to say:
Rita: I went once to ask about the food assistance, but they don’t have it anymore. They took it out. I know they stopped providing that.

Adriano (to Rita): They used to give food?

Rita: They did.

Adriano: Oh, for—for those who had [AIDS]?

Rita: Yeah. They gave food assistance every month. But I went to ask the social worker about it, and found out they cancelled that.

Adriano: I didn’t know that.

Rita: Well, I went to inform myself.

Adriano: Ah, I’m going to make a scene there. (Adriano’s voice begins to rise as he transitions to performing the hypothetical protest he says he’ll make at the clinic) Where did you go? Where did you find out? (Rita says something that Adriano drowns out; he continues his histrionic play-acting) I’m going to break stuff...Look, I want it; it’s mine! It’s a right!

Rita: (laughing) It’s not yours. Not your right.

Adriano: (seriously) No, but I mean, it’s a right, isn’t it? (incomprehensible, then resuming enactment of hypothetical scene) They have to pay! I’m going to break everything! (laughter)

Jokes aside, Rita and Adriano’s exchange is notable for several reasons. First, like Wílian’s comment, the couple’s conversation invokes the difficulty of obtaining assistance through the public health system based merely on seropositivity. Rita specifically constructs this difficulty as a reduction, given her knowledge that, in the past, the clinic had distributed a basic food package, called a cesta básica (lit., “basic basket,” it typically includes staples like rice, beans, pasta, sugar, cooking oil, etc.), to those diagnosed with AIDS. Her perception is grounded in reality—in particular, the changing nature of the epidemic. As more and more patients achieved viral suppression on ARV therapy, many were able to return to paid employment. Thus, serostatus alone was no longer considered to automatically indicate need, and policies were revised accordingly.
Like some other HIV-related work (most notably, targeted prevention efforts, see section “Observations in Controle social contexts” in Chapter 4), though, the provision of food assistance has not disappeared from Porto Alegre entirely; it has been delegated to civil society. For example, after registering proof of serostatus at Casa Vocação (one of the AIDS NGOs visited during the Institutional Mapping component of this project), both Wílian and Rita might have been able to receive food assistance and clothing once a month. It is an open question why Rita was not informed of this option when she inquired about nutritional assistance. Was the social worker unaware of Casa Vocação’s services? Did she conduct some sort of screening and determine that Rita was ineligible? Either way, the effect on Rita is the same: as far as she knows, such assistance is no longer available (Wílian clearly has the same impression).

The second noteworthy aspect of Rita and Adriano’s exchange is its illustration of the way most patients at the clinic I spoke with find out about and obtain benefícios: they ask the clinic social workers, nurses, or their doctors (who usually refer them to the social workers). Further, like Rita, seropositive members of couples in this sample typically did this only when they experienced a particular need; they did not make an appointment with a social worker to find out about the totality of services and assistance available to them.

It bears re-stating that during my time at the clinic, I did not observe any standardized attempt to convey this knowledge to patients. However, this could have taken place without being witnessed by me, specifically, during the ambulatório de adesão (see Chapter 2 for more details on this watershed appointment at the clinic) stop at the social workers’ office. Patients are given paperwork for the TRI during that appointment, and other programs could well be discussed. Given the potential psychological impact and side effects of initiating an ARV regimen, however, many patients may not be able to fully attend to such information at that
point. Although of admittedly limited utility for illiterate individuals, I also never saw any educational posters or pamphlets on the topic.\footnote{At one point during my fieldwork, I did see a pamphlet on this topic that had been produced by an NGO, but given the lack of interaction any of my research participants had with AIDS-related civil society, it was unlikely they would have come into contact with such materials.}

Finally, this segment showcases one of the few instances in which participants employed the word direito, or “right,” to discuss legal entitlements of HIV seropositive people. It forms part of a larger corpus of utterances involving this word that it is important to consider more integrally. As such, the next section places Adriano’s alongside other uses, and non-uses, of the term in an attempt to identify linguistic patterns and understand what they might mean for BMMC in relation to HIV/AIDS.

**Recourse to the Concept of Rights\footnote{It may be protested that the notion of “rights” employed in this chapter is inflexible and limited. I do understand that entire books have been written about the relationship between anthropology and rights (e.g., Nagengast and Velez-Ibanez 2004), as well as how conceptions of rights and citizenship have evolved in Brazil in particular (Holston 2008). Nonetheless, I have largely followed the lead of scholars writing on BMMC, who also tend to see “rights” in fairly juridical ways (but see Jolly and Jeeves 2010).}**

**Rights-based Discourse on HIV/AIDS**

Interestingly, Adriano’s usage of direito was offered somewhat facetiously, and it was not advanced with certainty. His query to Rita ("No, but I mean, it’s a right, isn’t it?") temporarily breaks the integrity of his performance; she answers indirectly and incompletely. Whether a seropositive patient at the clinic has a “right” to food is the question Adriano is actually posing, but his partner’s response focuses only on Adriano’s inability to “qualify,” as it were, for such a “right,” if one were to exist. This ambiguity surrounding seropositive people’s rights is never resolved; this was the only time the couple ever used this word to discuss AIDS-related benefícios, despite multiple opportunities to do so.
To provide just one example of this non-use, consider the following excerpt from a conversation with Rita. In it, we are discussing her disappointment at not being able to attend the support group for HIV-positive mothers-to-be, held weekday mornings at the clinic. She says she cannot get that much time off work without disclosing her serostatus, which she wants to avoid. When I ask if she fears that would lead to her dismissal, she says, “Of course,” and then continues:

Rita: The truth is I don’t know what the situation would be, you know? If everyone knew.

Shana: Yeah. They can’t fire you though.

Rita: Right, I know they “can’t”...because if I wanted to I could take them to court and win. They can’t fire anyone. (laughs) Even disabled people they can’t fire. (laughs)

Shana: Yeah, but it’s one thing to know your rights and another is how it works in the real world, right? (Rita: Umm-hmmm [affirmative]...) What a shame.

Rita: Yes, but that’s the reality. And even if people know, then you have (pause) prejudice.

Shana: And do you think there’s any way to fix that?

Rita: I don’t think so....It varies from person to person. Even those who are very educated don’t always accept it [meaning, HIV]. They know all about it and still don’t accept it. It’s their right. Everyone has the right to accept it or not.

Significantly, instead of decrying the possibility of being illegally fired, or asserting her “right” to work, Rita chooses instead to talk about the “right” of seronegative individuals to decide whether or not they will “accept” HIV. Thus, what could have been conceptualized as a public, political question of “rights” is rendered instead as a personal issue of feelings and disclosure.

Other Uses of “Rights”

Other participants in this research also employed the word direito, albeit not very frequently. They used it both in a legal sense, and more metaphorically. Iara, however, was the
only other individual in my sample to do so in relation to HIV; hers is a special case that will be considered subsequently. Felipe employed the term figuratively, for example, as he explained the choice to terminate the pregnancy that had led to Bibiana’s diagnosis. He said, “We came to that decision because we saw that it wasn’t our right to play with another life, you know?” Other participants offered pseudo-legal framings. Bibiana argued for extending self-determination to what she saw as its logical end when she commented: “I think you should have the right to take your own life.” Juliana used the term *direito* several times, in discussions regarding the quality of intimate relationship she felt entitled to, as well as more formal property rights. She invoked this latter idea in speculation about why she remained with Xavier, despite what she considered his poor treatment of her: “I think that it’s because when I went to live with him I had a house. I sold it to fix up a house we could live in together. So for me, I don’t know, there are times that I think I stay with him because I have a right. Because the money was half and half—half his, half mine.”

Wílian and Pamela’s use of *direito* was the most juridical. It occurred as they recounted things they had to take care of when they received custody of Wílian’s children. Near the top of this list was to “claim the rights” of his autistic daughter, who was entitled to disability payments. Her mother had never applied for them, and doing so required gathering and submitting documentation from several medical specialists regarding the girl’s developmental deficit. The couple was successful in this endeavor, and Wílian’s daughter was officially “retired,” meaning she was not expected ever to work and would receive a disability pension for the rest of her life.

Of course, using or not using a particular word can be fairly arbitrary as a measure of how people think; nevertheless, it can also be suggestive. At the very least, in spite of potential
variation regarding the basis for, and content and sanctity of, the concept of “rights,” these usages demonstrate that the concept itself has some currency for the couples in this sample. In addition, in two cases, the language of “rights” was expressed in conjunction with—that is, justified by—a biological condition. Further, one couple had demonstrated their ability to negotiate bureaucratic processes for claiming these rights. On the other hand, in many instances in which one might have expected the invocation of a rights-based discourse with regard to HIV, this did not occur.

In part, this may be due to lack of familiarity with the rights associated with positive serostatus. As stated above, most participants in this research seemed to have only a piecemeal understanding of this aspect of HIV infection. When I asked Bibiana, for example, if she received any benefícios from the government, she said, “No.” I probed, “Nothing from the National Social Security Institute?” She replied breezily, “I don’t know how that works; I didn’t even go to find out. The only thing I have—that I was even joking about [previously]—is the fare exemption card for the buses, you know?” Bibiana, like most of the other seropositives in this study, had not sought out much information about AIDS-related entitlements. Both she and her partner, Felipe, were employed at the time of this interview; in her estimation, they were not experiencing any unmet needs. Of course, lack of need does not always explain lack of knowledge about available programs and benefits; Rita and Adriano’s confusion about Programa Nascer (discussed above) is a good example.

**Rights and Work**

In contrast, participants were well aware of other types of rights—as well as the state’s role in securing them. Foremost among these were labor rights—which were also generally called benefícios—won through work in the formal sector of the economy, symbolized by the
carteira assinada. As described in the sketch of Wilian and Pamela, having a carteira assinada required a worker (and his/her employer) to contribute to the Brazilian social security system. In return, the worker was entitled to various benefits. Although the deduction in take-home pay had caused Wilian to opt to work informally, the vast majority of other participants spoke positively about the carteira assinada.

Bibiana, for example, denigrated her ex-husband for staying at a “dead-end job” for four years, where “he’s still making the same amount as when he started, with no carteira assinada, no vacation, no year-end bonus, and no participation in causes [i.e., contributions to social security or FGTS].” She herself had recently started a new job with a carteira assinada, and while she knew she did not yet have a “right” to vacation time, she was actively making plans for the following summer, when she would. Rita was likewise enthusiastic about the impact formal employment had wrought in her working conditions: “I have a set time to leave; I have a set time to start work. I also have a transportation voucher, guaranteed lunch, I have everything.” She noted she had now begun contributing to her FGTS and would have more rights when she left the job. Adriano concurred that this was a significant improvement. Months later, he reiterated his feelings on the matter, “I don’t work without carteira assinada, because it gives you some security, you know?”

This security (which could also be translated as “insurance”) was proving especially important for Jorge and Iara. When I met Jorge, he was unemployed, having lost his job as an overnight security guard. During the couple’s formal, joint interview, Iara explained to me why this had not been immediately disastrous for their household finances:

If you’ve worked with carteira assinada for six months, then you have a right to unemployment insurance, which is the salary you were earning. In truth, the amount of time you’ll receive this depends on how long you’d been at the job. In [Jorge’s] case, he’d been there for more than a year. So he’ll get unemployment for five months. Of course, he says he
doesn’t even want that money; he wants to get another job sooner rather than later.

Getting another job was not as easy as the couple had hoped; at Jorge’s individual interview a few weeks later, he had interviewed for one position, but had not been hired. Jorge had worked his way into a fairly specialized branch of security operations, and he said he wanted to continue in that direction with his career: “It’s good that I have these five months. I don’t need to jump at the first opening that comes up. After the five months maybe I’ll have to take whatever I can get, but that’s not my focus at the moment.” As the conversation continued, Jorge was able to explain to me the time frame in which he was required to file paperwork, how soon he could expect to begin receiving his unemployment benefits, the amount he would receive, and how that amount was calculated.

Other entitlements also figured in participants’ conversations. Xavier, for example, talked about having to avoid formal sector employment in order to maintain eligibility for his retirement pension, awarded on the basis of disability. Nonetheless, because this income was insufficient to cover the couple’s household expenses, he struggled to find informal work he was physically capable of doing. This required a delicate balance. As previously reported in the sketch of the couple, he said: “[If I’m retired], it’s because I can’t work, right? So if they find out that I’m doing something in another place, they’ll take my retirement pension away and then we’ll really be underwater! And how is it that I’m going to work (referring to his ill health)? That means if I’m going to work, it has to be something well camouflaged, something fairly light.” There was, in essence, a calculus of acceptability to be considered, based on Xavier’s current physical capability, economic need, and his understanding of rules regarding his benefits.

Recipients of benefits were not the only ones bound by such rules, however. The idea that employers are constrained by them as well is apparent in Milene and Renato’s discussion of
the job security offered by the latter’s certification as a *deficiente físico*, or a disabled person.

Milene claimed she was the one who encouraged Renato to pursue this, after he was fired without cause from a previous position. She explained, “So he …had problems at birth…. And he still didn’t walk right even when he was 12 years old. So…I said to him, ‘Because of your disability, could you get one of those special positions?’ Because with those positions it’s more difficult to fire someone…since the fine [for the business] is greater.” When I asked Renato about this, he elaborated further: “My job is a special position…nothing to do with serostatus, but as a disabled person…Businesses are obligated to have a certain number of workers that have problems, that are disabled. People who are missing a leg, or are blind—some disability. By law companies have to.” Because Renato’s disability was not readily apparent, I asked him how he had qualified for this status. He replied:

[I went] to the employment office and asked the girl working there, ‘How do I do this?’ She told me to go to the orthopedist, so I went to the closest one here…. I talked to the doctor. The doctor looked at my case and everything. I [used to have] the papers [documenting his birth, years of physical therapy, etc.], but my mom lost them in a flood; she lost the papers. But the doctor checked me over [and said], ‘I’ll give you documentation that you have a disability, sure.’

Renato was certified as partially disabled and had worked in this capacity for two years. He had also told his employer that he was HIV-positive. I asked Milene if the couple had worried about him being fired subsequent to this disclosure. Her response (analogous to Rita’s) did not focus on legal protections against discrimination for seropositive individuals. Instead, she said: “It’s like I told [Renato], ‘Now you have a special position as a disabled person…. It’s not like they can just throw you on the street.’ If he works like he should, and doesn’t miss, or only misses because of the medicine—in which case he’ll have the doctor’s excuse—if he does things right, they can’t just fire him.” In Milene’s rendering, then, HIV and disability intersect in Renato’s work life. HIV (and ARVs) may cause medically-necessary absences from work,
which will (ostensibly) be excused, but ultimately it is her husband’s disability status that protects him from being fired, as long as “he works like he should.”

Why one documented biological condition is considered more protective than the other is never made explicit, but seems to be based on the couple’s perception of employer self-interest (e.g., employers are required to hire disabled people; there is a fine for firing them). This is itself predicated on knowledge of deficiente físico as a category of worker (a particular type of “who-doing-what” that is available for a person to be), and an understanding of labor laws relating to disability. In order to benefit from this, Renato took steps to have his physical condition medically certified, that is, to be recognized as belonging to a category from which he could claim what Petryna would surely call biological citizenship. The most interesting aspect of all this, in terms of the questions explored through this research, is that, as Renato said, it has “nothing to do with serostatus.”

It is clear that the individuals discussed in this section made decisions about their lives based on detailed understandings of certain kinds of rights, usually labor rights and those connected to social welfare laws. There was never any suggestion that the usufruct thereof was dependent on personal contacts. The level of knowledge and conception of process for securing these rights thus contrast starkly with what research participants knew about rights granted to AIDS patients and how some of them seemed to believe such benefícios could be accessed. Wílian, for example, had weighed his options and decided that, given his economic situation at the time, the rights conferred by a carteira assinada were not worth the deduction in take-home pay they would entail. Yet when it came to HIV treatment, he seemed to attribute the care he and his adopted son received to the generosity of the clinic staff, not fulfillment of the

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114 Jorge did, however, tell me that it was much easier to obtain a position in his line of work if one came recommended by an individual the person doing the hiring knew. Such candidates, he claimed, often did not have to go through the same interview/qualification process as the others.
rights of seropositive people. Bibiana was thinking more than a year into the future based on her “right” to vacation time, but had not even inquired about the extent of her AIDS-related entitlements. Rita was excited about the guarantees of formal employment, but did not know how to access nutritional assistance (or believe that it was even available) based on her serostatus. Further, both she and her partner clearly thought of the city’s provision of infant formula to HIV-positive mothers as subject to personal influence, whether mine or the gynecologist’s.

**BMMC?**

This is not to say that potential dynamics of BMMC were absent from my data. Rita and Adriano were able to eventually access Programa Nascer to obtain formula and AZT for their newborn son. Once Renato understood his rights, he was able to arrange the disbursement of his FGTS. And there were other examples, although not related to HIV/AIDS. Wílian and Pamela were able to document his youngest daughter’s disability, which resulted in her “retirement” and status as a pensioner. Renato clearly mobilized his certification as a disabled person in obtaining employment he believed would be more stable than his previous jobs.

Renato’s wife, Milene, also traded in symptoms and diagnoses in an attempt to be recognized by the state as having a legitimate claim to a disability pension. During the period of this research she was involved in acquiring documentation (the results of an ultrasound, specialists’ opinions, etc.) for the appeal of her case. This hearing (the seventh) would be held before a judge, whose ruling, the couple believed, would be binding. The fieldnotes from my visit to them, the day before this hearing, record the following:

[Milene] told me, as I was leaving, that she’s getting ready—she’s not going to *se arrumar* (“get fixed up,” e.g., shower, shave, style one’s hair, apply make-up) from now until she gets home from there because they check everything—even your underarms! And I had noticed that she
hadn’t shaved—which I’ve never seen before. I guess the idea is to seem like you really need the money.

Whether due to this strategizing through personal hygiene, the medical documentation she had amassed, or simply the length of time she had been physically unable to work (more than a year at that point), Milene was successful in staking a claim to public assistance through the biological category of disability. Though her benefits would be minimal (because her previous contributions to the system were based on earning only minimum wage), she was able to explain them to me in detail. And while her assertions about the potential value of her disheveled appearance may seem redolent of the personalistic approach to benefits discussed at various points above, it is worth noting that at that hearing, the authority to grant Milene’s access to the benefício she sought actually did lay with one individual—the judge hearing her case. Also worth noting is that she had navigated the bureaucratic system of applications and appeals for over a year prior to this final hearing, something that would have been exceedingly challenging, had she not come to grips with its impersonal nature.

Whether Renato and Milene conceptualized these benefícios as “rights” remains an open question. Neither ever used the word direito to refer to their entitlements, although, given the various meanings associated with the word benefícios, this absence is inadequate as a conceptual litmus test. In addition, undue emphasis on use or non-use of the word direito may be more indicative of a certain fetishization or formalism than it is illuminating of social process. There is, nevertheless, an undeniable difference in the way this couple approached their disability-related entitlements and Renato’s AIDS-based rights, which were not well-understood. For example, neither partner acknowledged the legal protection from discriminatory practices in the workplace afforded to Renato qua a person living with HIV/AIDS (it being illegal for employers to dismiss a worker on the basis of HIV serostatus). In addition, although he had been
seropositive for well over a decade, it was only during the period of the research that they came to understand his right to access his FGTS. Thus, if a convincing case can be made for the occurrence of BMMC within this couple, it is far more likely to be built around the category of disability than HIV.

At this point, the overall lack of awareness of available benefits, and lack of consistent conceptualization of those benefits as part of an impersonal system (which is clearly the way participants interact with labor rights) make it difficult to characterize all but a few of the discrete acts described here as BMMC. It might be argued, nonetheless, that some of the other data presented above, for example Wilian and Rita’s interest in food assistance, or Bibiana’s act of obtaining her TRI despite having access to a car, evince incipient forms of citizenship, or simply other routes by which such a subjectivity can be developed. For example, absent intensive involvement with AIDS-related civil society (which, as noted above, catalyzed identity transformations for participants in several studies, e.g., Biehl 2007; Robins 2004), or a precedent of government responsibility for the physical and economic wellbeing of the populace (an important factor in the context of Petryna’s work), it may largely be through the receipt of HIV/AIDS-related benefícios that new forms of citizenship become visible to seropositive individuals, who then begin to construct or consolidate identities that allow them to take further action. More focused and sustained research, however, would be necessary to substantiate such claims.

Iara: An Exceptional Case

The data presented thus far provide a necessary framework for considering the case of Iara, the seropositive mãe de santo. Of all study participants, she had experienced the most severe physical effects of AIDS, and was the most recently diagnosed (approximately nine
months prior to our first meeting). The data I collected from Iara frequently contradicted the three main findings outlined in this chapter. In comparison with the rest of the sample, she sought out more information about HIV/AIDS-related benefícios, accessing it through not only social workers and other seropositive individuals, but also lawyers. She alone used direito in a serious way to refer to these entitlements, and did so more frequently as time went on. She understood her medical record as a resource, and managed it accordingly. Our first meeting had led me to expect none of this. As noted in the couple sketch of Iara and Jorge, when the former said, “Tudo que vem é lucro” (literally, “Everything that comes is profit”), I had taken this to mean that she did not really expect to receive benefits based on her serostatus; hence, I did not predict she would put much effort into trying to obtain them. That, however,proved not to be the case.

In addition to Iara’s memorable phrase, the fieldnotes from our first meeting contain other relevant observations. For example, she mentions that an unspecified doctor had told her she could use her diagnosis to “get her house and be retired” through the social security system. At the time she had protested, “But I don’t want to retire—I don’t need to. I want to work.” She continued, “Quit looking for benefícios. Não sou assim (I’m not like that).” It is unclear who she was addressing with this “Quit,” but it was the last time she made such a statement to me.

Though this conversation took place on Iara’s first day as a patient at the clinic, she was not naïve to treatment. For the eight months after her release from the hospital, she had been receiving care at the location where she had been interned and diagnosed. At the couple’s joint interview several weeks later, she explained that the hospital doctor’s brusque and unhelpful manner had prompted her switch:

I saw her be rude to a lot of other people. There was a man there, [who said,] “I need a doctor’s note that I’m not working. I want my social security.” [The doctor dismissively said.] “What do you want a note
“Can you not see that I’m in no condition to work? You’re not seeing that?” He was rude back to her and in one instant she gave him the documentation, you know? But she doesn’t usually give it. Her method is that you have to be working so you don’t think about things. But not thinking about it doesn’t help when my body can’t tolerate working….[That patient] was shouting there in the middle of the reception area….I just think, Shana, that it shouldn’t have to get to that point, you know? Making a scene so that people will take care of things.

The way Iara acted on her discontent with this doctor, however, was fascinating. Instead of inquiring as to how one might transfer one’s case, or simply showing up at the clinic with her chart and asking to be seen, she went to the HIV testing center located in the same building as the clinic, and participated in the counseling session and serological testing as though she had never been diagnosed. After the two-week turn-around, she went to pick up her results, and received a post-test counseling session, as required by law. She was then given an appointment as a new patient. Thus, according to the official record at the clinic, Iara began treatment in August of 2009; the doctor to whom she was assigned was unaware that Iara was not really an incident case.

As a result, once Iara was called into the consultation room, her physician began explaining all the initial tests she would need to complete. Only then did Iara reveal that she had been previously tested and was already taking ARV medication dispensed through another pharmacy (one administered by the state rather than the city). She even submitted her patient records from the hospital (which she had photocopied) for the doctor to review. When the inclusion of this information in her clinic chart was suggested, however, Iara demurred:

I [said,] No, this is a private thing of mine. [The physician] had some study going, about I-don’t-know-what; I wasn’t even interested, and I said I wasn’t going to give it to her. Then she [said,] “Oh, you can help me, you came at just the right time, just exactly.” Hmmmm (Iara frowns). I thought she was crazy. (laughing)...I said no because that way it doesn’t show up—I want to keep this thing under wraps. What if they go there to investigate? [Reporting someone else’s speech:] “No, but they don’t”—That’s when the social worker told me that they can’t do
that, it’s personal and all. (Shana: Right; Iara looks skeptical) They “can’t” until they do it, right Shana? I don’t know, so I’m going to leave it like that. No, I don’t want them to get interested in anything from the past. We’re just going to start from zero.

In this segment, Iara echoes an oft-heard sentiment in Brazil when she implies that there may be a difference between what exists on paper and what transpires in practice (in this case, the right to privacy vs. improper access to private medical information). In addition, she demonstrates an acute awareness of her medical record as a key witness to her condition that can be called upon and made to “speak” by virtually any interested party, whether to her benefit or detriment. In this, she is reminiscent of Lev, a patient in Life Exposed, who “knew, from a bureaucratic standpoint, that it was futile to pursue truth. Rather he became literate in the sciences and symptomatologies that were available to him. In this environment, Lev engaged his symptoms like an abacus” (Petryna 2002:138).

I began to suspect that the ability to “start from zero” had been more influential in Iara’s decision to switch treatment locales than she had admitted initially. This feeling was strengthened when, in her first formal interview after her initial clinic appointment, Iara compared it favorably to the hospital, despite what she characterized as the “strange” interaction with her clinic doctor, and despite the fact that the hospital had all the necessary equipment and specialists on-site to provide HIV care. Her explanation for this judgment was that, “[The hospital doesn’t] have a structure for...you know? For support or something like that. They don’t have that.” In contrast, her clinic doctor had already given her official documentation of her condition and the social worker “explained everything, how it works. At [the hospital] no one explained anything. They gave me [the same documentation her clinic doctor had provided] but they didn’t tell me what it was, or what I could do with it, you know?” This demonstrates the priority she had already begun to accord (or admit according) HIV/AIDS-related benefícios.
As the months went by, most of my visits to the couple’s home began with my request for an update on her various applications and petitions (an early conversation of this type produced the anecdote, related above, about the stigma Iara had confronted when obtaining her TRI). Nearly three months after meeting her, for example, I inquired about progress in getting her mortgage debt erased based on serostatus. She had hired a lawyer to help her with this and thereby learned more about her benefícios. Although she and her partner, Jorge, had jointly purchased the house they lived in, they had done paperwork that made it look as though he had sold his half to her, so that the whole amount would be eligible for forgiveness.

Unfortunately, it turned out there were legal irregularities with the title, as is common in working class housing in Porto Alegre (de Souza 2004). Whether the individual from whom they had bought the house had ever had a legal title to the property was unclear. In addition, part of the agreement involved a car Iara and Jorge used to have, which Iara explained they would get back through the debt forgiveness program. Angry phone calls had been exchanged and Iara and Jorge had even gone to the police over the issue. She sighed but smiled over the “drama” that was delaying the process.

Having been unable to confirm the existence of this benefício, at a later date I asked her to explain how it worked. She responded that, according to her lawyer, Federal law in Brazil provided for forgiveness of several kinds of debts incurred by HIV-positive people, including mortgages. Further probes about this process were waved away by Iara, who nonetheless seemed confident in the outcome.

This lawyer was also advising her about various justifications for retirement, and Iara reported that such considerations made a significant difference in the monthly pension awarded. For instance, one could be retired because of HIV (this was still possible, although more difficult
than before), even absent previous contributions to social security; however, the pension was equivalent to one minimum salary per month. A more attractive option if, like Iara, one had held formal employment, was being awarded *aposentadoria por invalidez* (retirement for disability), because the pension was calculated as an average of the salaries through which the worker had contributed to the system. Finally, she said there was the possibility of retirement due to psychiatric disability. Aside from providing marginally more income, Iara claimed her lawyer had told her that the only medical documentation that the state could not question is psychiatric, making this type of retirement the least contested in the courts.

Iara’s efforts on behalf of her bid for retirement were not restricted to obtaining necessary documentation from her doctor, policing the construction of her medical record, or hiring a lawyer, however. As time went on, she worried that her petition for *aposentadoria por invalidez* might be denied because she did not look sick enough. She therefore decided to concurrently pursue the psychiatric route. My fieldnotes from a visit in November of 2009 include her explanation of the procedure:

[Iara] claims that the social worker at the [clinic] told her to get a referral from her doc, go to the psych appt with [Jorge], say very little, keep her head down and have him explain that she’s been so depressed she can’t leave the house, at least not without him. She’s also supposed to cry a lot. They’ll probably give her anti-depressants, which she says she won’t take because she doesn’t need them. She’ll have to go see the psych several times. Then she said she’ll have to go to the [mental health emergency service] at the [health center], like she’s having a crisis—just crying and unable to talk. She said she knows all about this because this is what she was like when she was interned [at the hospital]—she said her hands shook all the time, she cried almost constantly, her legs were too weak to support her when she got out of bed, she’d lost 50 kilos. Remembering this, almost a year later, she was still visibly emotional about it.

In answer to my concerned expression and ingenuous question, “But, Iara, are you OK?” she adopted a patient, if slightly exasperated, tone but explained with a smile that she no longer

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115 This is the *Benefício de Prestação Continuada* detailed in Chapter 2.
feels that way; she has been able to deal with her diagnosis, although some days are better than others.

My question seemed to constitute an implicit, though unintended, challenge to the morality of her actions, because it prompted her to clarify that she would only resort to this if absolutely necessary. She was afraid, however, that she would be backed into just such a corner. She despaired of finding a job, especially if a prospective employer contacted her last one. Discrimination against HIV-positive individuals was illegal but almost impossible to prove, she said. This was the main reason she had not filed a lawsuit against the people who had fired her. Also, she argued, what would she gain, even if she won such a case? Most likely her old employer would have to take her back at the salary she earned before. Financially, this would solve her problem, but, she implored me, if they had fired her upon suspecting her HIV status, imagine how awful it would be to work there once they knew for sure! Roundly rejecting that possibility, she again mentioned that a judge might decide she did not look sick enough to retire—then what? If it was unfair for her to have been fired, it was also unfair that, as a consequence of that injustice, she would be forced to accept much less income per month than she earned made in decades. No, she claimed she would do whatever it took to earn a decent pension, saying, “Eu não quero um salário de pobre” (literally, “I do not want a poor person’s/miserable salary”).

At our next meeting, in early December, Iara was pleased to report that the R$350 (equivalent to one minimum salary) in temporary disability assistance she had received in October had increased in November to R$818, and in December reached R$1020. When I asked if this increase meant she had been “retired,” with her pension based on her previous contributions to the social security system, she said no, that she did not understand the
fluctuation in amount. She had been granted temporary assistance for six months, from October of 2009 through March of 2010, because of pneumonia. She reiterated her resistance to being retired solely on the basis of HIV:

> Since I always contributed [to the system], and I always had good jobs, I said no. I can’t accept that; I think it’s a misery....So I said to my lawyer that I didn’t want to do that; it’s for people that can’t work...but I’d have to prove that I live in a house that’s falling to pieces, that I’m dependent on someone, this and that, and that’s not the truth. I said to her that I didn’t want that, I wanted to have my rights, without having to lie.

At the same time, however, Iara had not abandoned her backup plan, to petition for retirement on the basis of depression caused by her serostatus. She wondered aloud if her clinic physician would help her if she simply told her what she wanted, or if it would be better to go through the steps she claimed the social worker had outlined for her, which involved Jorge going to doctor’s visits, and what she described as “embellishing a little bit” (enfeitar um pouquinho). She had, she noted, until March of 2010 (the expiration of her temporary assistance) for something to work out.

At our first visit of 2010, Iara told me she had tried to put the psychiatric retirement plan into action. Her physician, however, had referred her to a psychologist, which of no use since “they don’t provide documentation” in retirement cases. She attended two appointments, but was thinking more seriously about just explaining her situation to her doctor. When I asked what she would do if her physician refused, she said, “I’ll have to switch doctors.” She also noted she was still waiting to hear about the cancellation of her mortgage debt. Clearly, obtaining the benefícios she desired had become a high priority.

In late February, Iara told me she had switched lawyers and was collecting documentation for the petition to renew her temporary disability, as there was not sufficient time to prepare the application for definitive retirement before the current authorization expired. Her
new counsel had assisted Iara’s neighbor in her successful bid to retire and claimed there was “no doubt” Iara would also be successful. The fact that her temporary disability had initially been granted for a period of six months was by itself encouraging. This, in the lawyer’s opinion, together with the referral to the psychologist, and the report that Iara’s HIV physician had submitted (which described the patient as “seropositive, depressed, and obese”) provided sufficient grounds for such a decision.

By the beginning of August 2010, Iara had good news, which, although I had returned to the U.S., she shared with me via an Internet chat:

Iara: Guess what? I’m retired.
Shana: REALLY?!?!?! How did you do it? That process with the psychiatrist?
Iara: I had a hearing that the judge ordered. I have a huge infection in my mouth and on the day of the hearing my blood pressure was really high. So I didn’t need to pass myself off as crazy.

Her pension was set at around R$1200 a month (two and a half minimum salaries).

**Archetypal Patient Citizenship?**

Based on the foregoing presentation of data, the contrast between Iara and the rest of the sample, in terms of discrete acts undertaken with the goal of obtaining material assistance from the state on the basis of HIV/AIDS, is clear. She was more pro-active, more systematic, and more successful in obtaining HIV/AIDS-related **beneficios** than any other participant in this research. Her actions certainly fulfilled the conditions set out, as guideposts to whether patient citizenship was occurring, at the beginning of this essay. She was aware of specific benefits she could seek on the basis of her serostatus, she sought them, and she presented herself in biomedical terms with the potential to legitimate her claims. In addition, she conceptualized the process for obtaining those benefits as objective and juridical, and even justified her arguments
by recourse to talk about her direitos (rights). Based on an assessment of these criteria, Iara appears an archetypal patient citizen.

In explaining why she should constitute an exception to the general rule posed by the other cases considered here, economic factors must be considered. Of the six seropositive participants (those with direct access to HIV/AIDS-related entitlements) of this study, five of them had (at least somewhat) stable incomes. Three—Renato, Rita, and Bibiana—were formally employed; Wílian worked informally, but had a long history with the same company; and Xavier received a disability retirement pension roughly equivalent to two minimum salaries. Those five individuals all earned more than they would have through retirement exclusively on the basis of serostatus, had that even been a feasible option for them (and, aside from Xavier, who was already retired, their overall health would have precluded this). In addition, Rita and Bibiana had partners who were also employed; in both cases the men were the main breadwinners. And they were not the only couples with a dual source of income, a point to which we shall return shortly.

Iara, in contrast, had recently been fired from a fairly well-paying (her assessment) job, and was convinced it would not be possible to obtain another, given her physical condition and potential HIV/AIDS-related discrimination. Further, her partner, Jorge, was unemployed at the time of their participation in this study (although he subsequently secured a job he found acceptable). As such, unlike the other couples, Iara and Jorge faced a situation in which—unless circumstances changed—they would be without income in five months’ time.

This is not to suggest that, at the time of their recruitment to the study, Iara and Jorge were experiencing what one might call the greatest “absolute need.” On the contrary, Xavier and Juliana, Wílian and Pamela, and Renato and Milene (at the outset of the research), all earned effectively less, due to debt servicing or having to support a greater number of people with the
same amount of money. Further, the former two couples noted repeatedly that they did not have family on whom they could rely when times got very tough financially; this was not the case for Iara and Jorge (his mother frequently paid part of their mortgage). The material conditions of these couples’ lives were quite different. Compare the rough-hewn table and benches where Wilian’s family ate to Iara’s wooden dining room table with upholstered chairs, or Renato’s leaky roof and inability to afford an electric fan to Iara and Jorge’s and functioning personal computer with Internet connection. Economic need is clearly only part of the picture.

One also has to consider other aspects of social structure, beginning with the social welfare system in its entirety. This widens our view and foregrounds the question: What types of support are available to these couples, and through what avenues? The answer returns us to the dual incomes earned by couples other than those in which both members worked for wages. For example, although neither Milene nor Pamela worked outside the home, they both lived in dual income couples. Renato and Milene’s household budget was augmented during the period of this research via the granting of Milene’s disability pension. Likewise, in addition to Wilian’s earnings, his family could count on receiving his youngest daughter’s disability pension every month. The couples’ efforts to obtain these benefícios, as previously explained, could certainly be considered biomedically-mediated citizenship, though not related to HIV/AIDS. They serve, however, to highlight an important limit to how profitable or helpful the exercise of such an identity, and claiming of associated rights, can be to seropositive individuals.

There is a difference between rights conferred by HIV serostatus alone, and rights won by other means, to which HIV provides special conditions of access. What might be called “direct” rights to assistance require people living with HIV/AIDS to fulfill few additional criteria, and were actually quite limited at the time this research was conducted. Most notably,
these direct rights include free legal assistance with HIV-related issues, and, in Porto Alegre, a fare-exempt TRI. Also, with supporting documentation (both medical and of the patient and her/his family’s finances), economic assistance in the amount of one minimum salary a month is available for those unable to support themselves. Seropositive people can attempt to claim these direct rights even without previous contributions to the social security system. But Wílian’s overall health, for example, would have disqualified him from the latter benefício and, in any case, he usually earned more than one minimum salary in his work as a mechanic. While he was eligible for a TRI, his professional expertise allowed him to maintain a vehicle, which he preferred since it enabled him to transport the rest of his family as well (they would have had to pay if riding the bus).

The benefício that might have proven the most helpful to Wílian was the FGTS, but this is only an indirect right of PLWHA, or what might be called an “AIDS-mediated” right. That is, positive serostatus is one of several qualifying conditions that allow a worker to access the mandatory savings account created through formal employment; absent a period of formal employment, however, there is no account to liquidate. Such was Wílian’s case. Despite serostatus and need, his position of relative marginality (symbolized by his employment status), precluded him from this particular exercise of patient citizenship. Though the details are different, the end result brings to mind Fraser’s (2010:552) study of drug users dealing with Hepatitis C, in which she observes that, for some individuals, “further engagement with corporeal modes of enacting a responsible, citizen-like self depends on the presence of factors that themselves are markers of prior citizenship status: decent housing, employment, and so on.”

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116 It should be noted that the Benefício de Prestação Continuada is not a benefit that is exclusive to AIDS patients; therefore it is technically an “AIDS-mediated” benefit, though one’s eligibility does not depend on previous formal employment.
Renato’s situation differs from Wilian’s in two structurally important ways that both involve questions of “eligibility.” First, because he worked with carteira assinada, Renato’s serostatus does grant him access to his FGTS. The “less marginal” social position (formal vs. informal employment) he occupied initially thus functions as a kind of economic “guarantee.” Second, he has created (through biomedical documentation) another identity through which he can stake biologically-mediated claims on the state: disability. The incentive for businesses to employ disabled individuals is literally worth more to Renato than an AIDS-based pension would be (for which, in any case, he was likely too healthy to qualify). Wilian cannot use his biology to obtain similarly-secure employment because the hiring of HIV-positive people is not protected or encouraged in the same way. These contrasts demonstrate that both what the state extends as “rights” for seropositive individuals, and how those rights may be claimed are important factors to weigh when considering patient citizenship.

Returning to Iara’s case, neither she nor Jorge had any other biomedical category through which they could stake a claim for assistance, but Iara had been formally employed. She was therefore structurally advantaged, since any pension amount she might receive would be based on her previous earnings.¹¹⁷ Further, her health did not preclude her from applying for disability, unlike the other seropositive participants. Her situation also, however, highlights a path by which relative economic advantage—a “[marker] of prior citizenship status”—can translate into “further engagement with corporeal modes of enacting a responsible, citizen-like self” (Fraser 2010:552).

As both Petryna and Biehl argue, rights have become (or perhaps have long been) part of a market. Returning to Lev, one of the poterpili in Life Exposed, Petryna (2002:138) documents

¹¹⁷ Iara never mentioned receiving the FGTS, but the account should have been disbursed to her when she was severed from her last position.
the informal systems of exchange in which he participates, providing access to specialists, material goods, and educating other patients about symptoms and documentation. Exchange is also at the heart of the experience of the profoundly marginalized HIV-positive individuals in Will to Live (Biehl 2007:324), who discover “an unprecedented opportunity to claim a new identity around their diseased and politicized biology, with the support of international and national, public and private funds.”

But Iara’s trajectory suggests a new way “rights” are being commodified and, facilitated by HIV/AIDS, incorporated into the neoliberal context in which these participants’ lives unfold. Iara is distinguished from the rest of the sample by the extent to which she claimed rights as a seropositive person, but also by her decision to hire an attorney. Though the small sample size for this research severely limits the conclusions that can be drawn from this observation, it does prompt an unsettling notion that should be considered, namely, that the process of claiming rights through patient citizenship is being, in a sense, privatized. Previously, patient citizenship was seen as at least potentially disruptive of systems of privilege and social exclusion, a democratizing impulse that might work to the benefit of even the most disadvantaged seropositive people. Iara’s experience suggests this process may now be most effectively negotiated by those with the means to pay.

Finally, although it was largely implicit in this chapter, any attempt to explain Iara’s more consistent performance of patient citizenship must attend not only to economic and social capital (i.e., the resources to which one has access and one’s position within a social system), but also to notions of identity. As Mfecane (2011:131) recommends, “A researcher who explores [therapeutic citizenship] must pay attention both to the personal narratives of a client attesting to his or her changed subjectivity, as well as to the social context in which he or she lives as an

118 See also Biehl 2011; Biehl and Petryna 2011.
HIV-positive person.” As the presentation of data throughout this dissertation demonstrates, all participants were at least minimally capable of reproducing biomedical discourse with relation to HIV/AIDS, including applying it to themselves (or their partners) in ways that would prompt their recognition as a sanitary citizen. However, the majority of seropositives consistently foregrounded other identities. For example, Wilian and Xavier talked about themselves in the stereotypical terms of masculine sexual desire, or, alternatively, as a worker and father, or an ex-addict, respectively. Rita also adopted a gendered trope, one that emphasized emotionality and sexual inexperience seen as appropriate for “good” women. Renato opted to portray himself simply as having a “normal” life, while Bibiana embraced being atypical, whether as a worker, a mother, or a romantic partner. While each of these individuals did make statements that revealed a notion of the self *qua* seropositive person, in no case was that the dominant presentation.

As detailed previously (principally in Chapters 5 and 6), Iara also resisted association with HIV. For instance, she contrasted her sexual practices with those of CSWs (thereby implicitly assuming a version of the “good woman” identity), and heavily emphasized her position as *mãe de santo*, epitomizing a spiritual and, at times, almost maternal ethic of care. Her possibilities for such non-HIV-related presentations of self were nonetheless impacted by her inability (physical or psychological) to engage as before in what she considered normal activities, principally paid employment, work in religião, and sex. Iara’s despair over obtaining another job was described above. A similar, if partial, sense of loss pervaded her comments on her spiritual practice and physical intimacy. After she resumed working with believers in her home, she said, “Of course it isn’t the same energy to do it that I had before, it has to be slow, you know? But I do it. Like today, I scheduled some [spiritual] cleansings; they’re all coming at
night. So I do one, I sit a while, I do another…” As for sex, she smiled ruefully as she confided, “Oh, I’m going to tell you: after this disease here, it loses a little bit of its shine.”

Because of the centrality of work, religion, and sex to her sense of self, whenever she experienced a limitation in these areas, it brought her serostatus to the fore, obligating her, at least at those moments, to conceive of herself in terms of HIV. As a result, Iara could not comfortably relegate HIV to the back of her identity closet, to be pulled out and slipped on only when necessary. Recall her comment to me: “Living with this disease, every day you learn something different. But—oh, I don’t know, it’s strange. There are times that—like I told you, you forget you have it, but there are days that you remember every minute. There are days you remember every minute.” In juxtaposition, other seropositive participants at least claimed that they barely noticed their serostatus on a day-to-day basis. Wílian, for example, told me, “I’m used to it because it’s just part of my life.” Even Bibiana, the other most recently diagnosed participant said, “We just forget, you know? I say, ‘But why am I going to remember?’ I only remember when I have to use a condom to have sex with Felipe.’

The impact HIV had on Iara’s life—both physically and emotionally—was considerable and lingering. As a result, she was less able, in comparison to the rest of the seropositive participants, to conceive of herself in terms unrelated to her serostatus. This, coupled with the more urgent perception of need she and Jorge were experiencing at the time they were recruited for this study, and the greater financial benefits she was structurally positioned to reap from exercising her direitos, likely contributed to her more extensive recourse to acts of patient citizenship. In essence, she had little to lose, and what she stood to gain was significant enough to warrant facing the stigma to which all participants in this research feared they might be subjected.
Conclusion: The Materiality and Meaning of BMMC

Throughout this chapter, as data have been presented they have been discussed in terms of their relevance to the research question being considered, namely: Do these serodiscordant couples conceive of risk as an opportunity or a commodity that can be exchanged for goods, services, or status? To what extent do they engage in what has variously been called biological or patient citizenship on the basis of HIV/AIDS? Due to differences in context (historical moment, political regime, individual socioeconomic position, etc.) with previous scholarly work on this topic, participants in this research were not expected to manifest these dynamics in exactly the same way as previously observed. As with any social process, variation was anticipated, and seen as potentially significant. Nonetheless, the development of some sort of metric was necessary in order to answer the research question. Thus, basic criteria were abstracted from important sources on these new forms of citizenship, and these criteria were applied in the analysis presented here.

In general, most participants lacked important knowledge about direitos or benefícios associated with positive HIV serostatus, and there was a marked, although by no means unanimous, tendency to conceive of access to assistance they were aware of as an effect of (inter)personal, rather than programmatic or juridical, factors. Thus, applying the label of patient citizenship frequently seemed questionable; notions of therapeutic clientship might be more appropriate for this sample. The idea was entertained that some of the data reported might indicate an incipient form was present in certain couples, or that perhaps the development of patient citizenship under these circumstances would follow a different trajectory. More research would be required before doing anything more than suggesting these as possible explanations for my observations. Overall, however, it seems that, most couples in this sample are simply too
well-off (economically and in terms of the identities to which they have recourse) for BMMC practices to be “worth” pursuing. On the other hand, Iara’s actions and discourse satisfied the criteria proposed as prerequisites for asserting the presence of patient citizenship. Personal economic circumstances, structural factors, and considerations of identity were offered as reasons for her exceptionality.

In terms of the larger issues raised by Richey (2012:842) with regard to the distinct effects of a practice of clientship vs. citizenship, it seems that these HIV-serodiscordant couples took little opportunity to contest the Brazilian status quo, “in terms of claiming rights on the basis of equal human worth.” Of course, these couples do not belong to the most oppressed stratum of Brazilian society—*marginais, abandonados*—so they do not have to struggle so unceasingly to be accorded minimal standing as legitimate members of the body politic. It is, however, largely through access to ARVs, provided by the Federal government, that the seropositive members of these couples have avoided that fate. As evidenced in the academic literature, as well as comments made by Iara and Renato, those with the skeletal frame still associated with AIDS in Brazil are heavily stigmatized.

To varying degrees, all of these couples are invested in escaping that experience. As such, it is logical to conclude that, in terms of BMMC, it is not only the meagerness of the associated financial and material rewards to be gained, but also the required declaration of serostatus that dissuades minimally self-sufficient seropositive individuals from these practices. Therefore, the lack of patient citizenship among this sample, like the semantic quarantine and the discourse of normality, can be explained, in part, as a reaction to the prevalence of HIV/AIDS-related stigma in Porto Alegre.
CHAPTER 8: CONCLUSIONS & RECOMMENDATIONS

Introduction

Having provided supporting evidence for each piece of my argument along the way, in this last chapter, I offer a streamlined review of the dissertation as a whole. In the first section below, I restate the most important findings from each chapter. In the second section, I list the research questions and answer them, distilling the conclusions drawn from the data into their simplest, most highly synthesized form. The third section contains recommendations for policy based on the data presented in the dissertation. In the fourth and fifth sections, I briefly cover plans for disseminating the results of this research, and ways in which I would like to build on the project in the future. Finally, I close with a short reflection on discourse, AIDS-related stigma, and hope.

Risk and Heterosexual HIV-serodiscordant Couples in Porto Alegre: The Dissertation in Review

The dissertation began by presenting what might fairly be called the “genealogy” of the research. Particular experiences I had in Porto Alegre, and impressions formed through exposure to the academic literature on HIV/AIDS in Brazil that left an indelible mark on this project simply had to be acknowledged from the outset. The switch from a primarily political economic framework to an analysis that prioritized discourse also merited specific mention. In this endeavor, I hope to have avoided solipsistic excess, producing instead my own version of that recognizable “arrival in the field” anthropological narrative that, as Pratt (1986:32) notes,
“play[s] the crucial role of anchoring [the subsequent] description in the intense and authority-giving personal experience of fieldwork.”

Next, I offered the reader a glimpse into the socio-cultural, epidemiological, and historical context in which this research was carried out. Some of these characteristics, like Rio Grande do Sul’s marked difference from the rest of Brazil, along with the proportional severity and general contours of the state’s AIDS epidemic (with the city of Porto Alegre as its epicenter), justified the formulation and location of this particular research project. Others provided the background necessary for making sense of the findings. Here, the history of local and national responses to the epidemic—shaped by historical forces, and the notion of health as a human right—as well as the general structure Brazil’s public health system, were of foundational importance.

After thus setting the stage, I examined the local context in which the seropositive Porto Alegrenses participating in this study receive HIV/AIDS treatment. The clinic’s location, evolution over time, and current functioning were all detailed. This information is important because, for the seropositives in my research sample, clinic interactions constitute a primary way they learn how to “live positively.” Challenges experienced and presented by individual patients notwithstanding, the effectiveness and routinization of the biomedical management of AIDS was evident. Nevertheless, in spite of scientific advances in treatment, and laudable public health and legal measures, AIDS-related stigma remained a primary concern of clinic patients.

I then turned to a selective overview of scholarly perspectives on sex-related risk for HIV, including a section on serodiscordant couples. Focusing on work in anthropology and public health, I traced the development of prevalent understandings of risk from “risk groups,” to “risk behavior,” to approaches that are both (though often not simultaneously) more quantitative,
and better contextualized. Increased analytical attention to social inequality, in particular, has widened the scope of factors to consider when thinking about risk in both disciplines.

As a heuristic for exploring the voluminous literature on HIV/AIDS in Anthropology, I attended to conceptions of risk as manifested in works I classified as idealist, materialist, or integrations. The idealist treatments showcased the importance of meaning and power in heterosexual intimate relationships, specifically as they are structured by gender, sexuality, and reproduction. One element that proved critical to understanding the data presented in later chapters was the process by which mutually-constitutive conceptions of hegemonic masculinity and femininity in Brazil typically encourage sexual behavior that facilitates exposure to the HIV.

While idealist notions of risk often focused on the power of discourse to influence decisions erroneously attributed solely to individuals’ “free choice” (e.g., to use a condom or not; to have multiple partners or not), materialist conceptions frequently addressed factors over which social actors are assumed to have little control: the multiple scales of political economy and history. At the most local contexts—particular neighborhoods, for example—where people might be seen as more capable of agency, however, these depictions demonstrated that the unequal distribution of material social goods continues to have consequences in terms of greater vulnerability. Employing the idealist-materialist lens illuminated the diversity of considerations that structure sex-related HIV risk.

Overall, detailed ethnographic accounts and anthropology’s tendency to problematize or historicize categories and phenomena seen as “natural” have been the discipline’s primary contribution to the HIV/AIDS literature. Anthropological work reviewed here that integrates materialist and idealist approaches often displayed both of these tendencies, and viewed the body as a primary site where material factors and ideational forces converge. These antecedents were
crucial in preparing the ground for more recent critical, holistic considerations of risk and embodiment that understand risk for HIV, and the virus itself, as potentially polyvalent. Specifically, analyses of the commodification of HIV suggested that when seroconversion is celebrated, “risk” takes on meanings that differ radically from its most common usage.

Finally, the literature review turned to the particular circumstances under which risk is experienced by HIV-serodiscordant couples. Despite an initial tendency to disregard the conjugal context of potential exposure, and treat any divergence from biomedical orthodoxy as “denial” or dysfunctional, an analysis of this body of work revealed that a flexibilization of sorts appears to be under way. New and profound consideration of practice and subjectivity within these couples revealed that serodiscordance, and the “opposite” serostatuses that supposedly constitute the phenomenon, are multiple, contingent, and, evolving—or, as Biehl and Locke (2010) might say, “becoming.” If such multiplicity is to be adequately understood, it must be through its manifestation in specific, culturally and historically situated contexts.

This study was designed to pursue just such an examination. After reviewing the relevant literature, the dissertation explained in detail the various components of the research, the methods used in data collection, and the steps taken in analysis. Aiming for a deep sense of context in which to situate the experience of serodiscordant couples, basic anthropological methods of participant-observation and interviewing were conducted with various groups. Over the course of seventeen months, I engaged in “institutional mapping” (which focused on municipal and state government, public health entities and locales, as well as AIDS-related civil society in Porto Alegre), work at different therapeutic contexts, and repeated interactions with six, heterosexual HIV-serodiscordant couples. Collected materials were digitized and/or transcribed and subjected to thematic and discourse analysis.
Data from the research were presented in several ways: through an in-depth overview of each couple, through a fine-grained analysis of particular aspects of discursive production across couples, and through an examination of specific actions taken (or not taken) in the course of their experience as HIV-serodiscordant couples. Prior to the presentation of the data, however, I discussed my conception of the nature of social reality in sufficient depth to uncover the connection between life, research methods, and analysis that lies at the heart of this study. Specifically, I employed an understanding of existence in human groups as fundamentally shaped by discourse, which both reflects and creates the conditions in which we lead our lives. Far from being merely what is said or written, however, discourse is the totality of communication, thought and enacted, in support of identity and relationships with other people. Discourse thus has a material component, and is inherently dialogical. Its meaning cannot be ascertained in isolation from the context—historical, economic, and cultural—of its production; therefore the particular mode of discourse analysis adopted in this dissertation was ethnographic.

Applying this lens to collected data, I produced sketches of each couple, intended to convey a sense of their history, personalities, and the texture of their daily lives, including HIV’s place therein. The significant forces impacting them included: social class or current economic situation; gender, sexuality, and reproduction; serostatus; and stigma. Seropositivity and discordance, lived in diverse ways, were visible to varied degrees, whether as elements of a larger backdrop or more prominent issues. Always approached from within a conjugal frame, these phenomena were associated with a range of reactions, from anxiety, to irritation, to care and support. Three of the six couples consistently used condoms; three did not. No clear pattern was discernible between prevention behavior and class, gender, serostatus, amount or explicitness of communication about HIV, or perceptions of stigma. The generalization the
sketches supported was that, while ARV treatment had largely rendered HIV a secondary medical concern, socially speaking the stigma attached to the disease remained a preoccupation that arose spontaneously throughout my interactions with these couples.

The holistic understanding of serodiscordance conveyed through the couple sketches was subsequently deepened through a targeted discourse analysis. The particular aim was to unearth prevailing constructions of risk and the mechanics of their negotiation within couples. To this end, expressions occurring across the majority of couples regarding HIV’s relative unimportance were subjected to close scrutiny, resulting in the identification of what I call the “discourse of normality.” Through this discourse, speakers often claimed to have “a normal life;” however, the implicit referent in such constructions was the life lived by seronegative people, a product of hegemonic ideas that stigmatize positive serostatus. Switching focus slightly, I examined one participant’s (Xavier) discursive production around the topic of HIV transmission, in order to illustrate how constructions of risk manifested through discourse.

Patterns identified in that case study, involving linguistic practices, stigma, and non-serostatus related identities, were also present in the discourse of other participants. These patterns revealed that through talk about HIV transmission, employing the terms contamin*, passar, and pegar, participating couples engage in a collaborative resignification of serodiscordance as it pertains to their union. This re-imagining is effected through a suite of linguistic strategies I called the “semantic quarantine,” the immediate object of which is to discursively isolate the relationship and its constituent members from lexical elements associated with stigmatized identities. The quarantine also permitted foregrounding the performance of non-HIV-related identities, and had as its ultimate goal the preservation of the viability of these couples’ intimate relationships.
Having explored the way serostatus and couplehood intersect in the subjectivities of the members of this sample of HIV-serodiscordant couples, the dissertation retained this understanding as a backdrop to further analysis. Specifically, I hoped empirically observable behavior around HIV transmission and/or pursuit of benefits or rights associated with infection, might reveal underlying notions of risk. I asked to what extent the couples’ actions could be meaningfully interpreted through constructions that posit risk or the virus itself as an opportunity, as a commodity, or as a basis for the exercise of citizenship. The relatively new body of work oriented to this last consideration was reviewed, and aided in the development of criteria by which to evaluate the data reported.

To summarize the results: no evidence was found of risk as an opportunity, and little evidence supported interpreting participants’ actions as stemming from notions of citizenship and rights (although Iara was a possible exception to this trend). Some important potentially limiting factors on such expressions were highlighted, however. First, there was a lack of knowledge about HIV/AIDS-related benefits and how they worked. Second, the relatively low monetary value of this assistance, compared to participating couple’s incomes, reduced its attractiveness. Finally, as has become a refrain in this dissertation, the possibility of having to confront AIDS-related stigma when accessing or using these benefits may have contributed to the couples’ diminished motivation to obtain such aid.

To the degree that any of the above-mentioned perspectives appeared to characterize participants’ behavior, it was clientship (a specific form of commodification) that proved most useful. This suggested the application of institutionalized strategies for dealing with unequal distribution of resources, power, and social status to the therapeutic domain, rather than the development of new modes of relating to the state. I concluded that, at the very least, for these
six serodiscordant couples, there is potentially more continuity in the social process for accessing HIV treatment than other scholarly treatments might recognize. The important implications of this finding, both for the individual couples in this research and for Brazilian social structure as a whole, are explored in the next section, which specifically addresses the research questions animating this dissertation.

**Answering the Research Questions**

The following research questions were addressed in this dissertation:

- **RQ1:** What place does HIV occupy in the everyday lives of a sample of heterosexual, HIV-serodiscordant couples in Porto Alegre, Brazil?

- **RQ2:** How is risk, specifically the risk of HIV transmission, constructed and negotiated by these couples?

- **RQ3:** More specifically, do these couples conceive of risk for HIV or the virus itself as an opportunity (Zaloom 2004) or a commodity (Crane et al. 2002, Abadía-Barrero 2002,) that can be exchanged for goods, services, or social inclusion/status? To what extent do they engage in what has variously been called biological or patient-citizenship on the basis of HIV/AIDS (Petryna 2002, Biehl 2007)?

A succinct answer to these questions is that, while the biomedical management of HIV/AIDS was relatively unproblematic for the participants of this research, the sociocultural management of the virus—both within the couple and vis-à-vis wider society—presented varied challenges, which could be complex and significant. To flesh out what I mean by this, I take each piece of the above sentence in turn, drawing on the results presented in Chapters 5-7.

First, it should not pass unremarked that all of the seropositive partners in this study had been prescribed ARVs as a result of being diagnosed with AIDS, and none of them had ever been unable to fill those prescriptions. While some participants had, in the past, received a 15 (rather than the normal 30) -day allotment of particular drugs temporarily in short supply, they had never been forced to change their pharmaceutical regime due to exhausted supplies, or go
without medication. Clearly, as stated in Chapter 4, this “evidence of access” is in part an effect of recruiting from a clinic context (in that those who transit through this space obviously have not been excluded from the health system; those who are cannot be recruited), but it remains an incredible achievement.

The consistent supply of effective drugs, as Beckman and Bujra (2010:1056) noted for the Tanzanian context, allowed “treatment recipients [to] ‘recover,’ turning from ‘patients’ back into ‘persons’.” Many of the participants in this study emphasized that an AIDS diagnosis was no longer what it had been in the past: a “death sentence.” As Jorge phrased it, “We know it’s not like that anymore. Before, people imagined, ‘Ah! I’m going to die in two months. I have HIV; I’m going to die.’ No. There are people who have been living with [the virus] for fifteen, twenty years.”

This extended survival time, and the relatively good health seropositive participants enjoyed, allowed typical individual and conjugal concerns to return to the fore in daily life. Thus, for most seropositive and seronegative members of these couples alike, financial worries far outstripped any mention of HIV as their “greatest source of stress over the last week.” In addition, the way gendered dynamics played out within the dyads, as well as the symbolic importance attributed to reproduction, often recalled findings from the academic literature on Brazilian heterosexual intimate relationships in general. Many participants claimed HIV was such a non-issue that they had a “normal” life, or that HIV was the least of their troubles. For the sample as a whole, HIV was being held in check by available treatment. While seropositives sometimes admitted to tiring of their daily regimen of pills, the medical

119 Bibiana, Felipe, Jorge, Iara, Renato, Milene, Adriano, Rita, and Juliana all made comments echoing the metaphor of AIDS as a “death sentence,” either to express past conceptions or contrast the contemporary situation with the past.
management of HIV occupied relatively little conscious space within the couples’ daily existence.

If death from AIDS was once a shadow that stalked seropositive people, for these couples, it had receded. But in its place lurked AIDS-related stigma. The most consistent finding of this study—across couples as well as modes of analysis—was the conviction that AIDS-related stigma is still prevalent and powerful in Porto Alegre. Many participants (again, seropositive and seronegative alike) practiced selective disclosure of serostatus out of fear of prejudiced reactions on the part of the general public, acquaintances, friends, and family members. It was clear that HIV meant different things, to different people, in different contexts.

Most participants explicitly dissented from still-influential constructions linking HIV with stigmatized “Others,” like MSM, IDUs, CSWs (all of which played important roles historically in the epidemic in RS, and maintain higher than average prevalence rates), and the “promiscuous” in general. And yet, as inhabitants of the cultural milieu in which these hegemonic discourses circulate, their unspoken assumptions and implicit points of reference illustrated the degree to which they remained influenced by such ideas. The discourse of normality is just one example of participants’ efforts to contest stigmatizing connotations of HIV that, nonetheless, are rooted in these very associations. That is, the statement that life as a seropositive person (or in a serodiscordant couple) is “normal” was intended to draw the interlocutor’s attention to the lack of any distinctive quality characterizing such an existence; it was an assertion of sameness. The question is, however, “sameness” with what? The unacknowledged basis for this comparison was life as a seronegative person (or in a seroconcordant, HIV-negative couple). Therefore, at the same time words were used to portray
one reality (life with HIV is “normal”), they also reified the reality (i.e., life with HIV is not “normal”) from which they attempted to dissent.

Discursive production within these couples about HIV transmission also demonstrated the prevalence of stigma. The frequency of, and particular linguistic devices employed in, references to the seroconversion of other people (whether general, hypothetical, or known) differed dramatically from talk about seroconversion within the couple. Strategic use of contamin*, passar, and pegar, permitted speakers significant latitude in suggesting moral culpability for HIV, which, while sometimes heavy in relation to third parties, almost invariably evaporated when the source of infection was oneself or one’s partner. These words also provided flexibility in assigning agency in potential or actual seroconversions. Again, while responsibility for incident infections among others was often attributed in ways that reflected common biomedical parlance, in contrast, within these serodiscordant couples, the seronegative partner was virtually always portrayed as the active agent, allowing the seropositive individual’s actions to drop out of sentences entirely. Different words thus called into being different realities, in which HIV and risk meant different things. The need to linguistically create a “safe space,” where particular loves are re-imagined and rendered livable, was not solely a response to forces exogenous to the couple, however. The collaborative, albeit subconscious, discursive efforts to protect both the relationship and (especially) the seropositive partner from stigmatizing associations—those actions that constitute the semantic quarantine—would not be necessary if those associations were not part of the speakers’ worldview.

Finally, I would like to address the distinction between clientship and citizenship, and some implications of the findings of this research, as mentioned above. First, the general absence of evidence for BMMC within this sample of serodiscordant couples should not be taken
to cast doubt on the existence of this dynamic, whether in Porto Alegre, Brazil more generally, or worldwide. In fact, I believe I saw BMMC at work in the very health center where the clinic is located. Specifically, I observed members of the support group I attended for homeless alcoholics (see Chapter 4) contest their exclusion from the premises by appealing to analogous logics. In addition, patients who appeared to live in similar situations were present in the clinic (although they were either ineligible for this study, or I could not ascertain their eligibility), and I can only presume they encountered the same obstacles to access. This is part of what grounds my conclusion that my research participants did not engage in BMMC: they were not poor or excluded enough to be forced to resort to such practices.

Regarding the implications of the contrast between clientship and citizenship, both micro- and macro-level consequences must be signaled. On the macro-level, the lack of empirical support for the practice of BMMC among the poor (but not destitute), and working- or lower-middle class patients in this sample severely limits the emancipatory potential envisaged for these hypothesized, novel ways of relating to the state. That is, if these seropositive individuals are not conceptualizing their interactions with Brazil’s health system in terms of rights and equality, then that frame cannot be transferred to, and work to destabilize, other systems that have historically reinforced social inequality within the country. Of course, findings from this small sample cannot be extrapolated to SUS patients as a whole. However, patients from similar class backgrounds constitute a large percentage of SUS users; as such, it is worth investigating, rather than assuming, how they understand their access to these services.

The citizen/client distinction also has ramifications for what transpires on the micro-level, between individual patients and providers. We must recognize that users who approach the health system from these divergent orientations may engage in the same discrete acts—or, at
least, acts that appear to be the same, from the provider’s point of view. But such acts can be invested with radically different meanings by patients, leading to different outcomes. An example may be useful here. From the perspective of Renato’s physician, the 35-year-old, seropositive male appears to be a paragon of adherence. Renato faithfully keeps his appointments, and picks up his ARVs on time. The results of serological testing suggest he also complies with his dosing schedule: his viral load is undetectable. In addition, Renato takes condoms with him when he leaves the clinic. The physician (based on Renato’s report) does not ask about his patient’s sexual or affective partners, and Renato seems unlikely to tell the truth, even if asked. Thus, to the doctors who are treating them, Renato and a patient like Wílian, for example, belong to the same “class:” the model patient.

Model patients are those who are treatment-compliant, but there is an additional level of meaning at work here. “Model” patients are also those who fit seamlessly into the system, by using it according to its design. As clearly outlined in Chapter 2, SUS was designed to provide healthcare to all—through an idiom of rights. Hence, model patients are also those patients who conceptualize and demand access to the system in this same idiom. Model patients are patient-citizens, not therapeutic clients.

Renato, despite his doctor’s impression however, is not a model patient as judged from the perspective of biomedicine as practiced in the clinic because he and Milene do not use condoms. He takes them home for the sake of appearances—and also because Ivar likes to use them as balloons. In addition, Renato’s personalistic conception of his relationship with his physician suggests that, rather than a “citizen,” he is a “client.” Multiple details might be seen to support this argument: he wished to avoid angering the doctor by reporting non-use of condoms; nonetheless he accepts them; at least twice in discussions with me he pointedly noted the
“praise” he receives at the clinic on the basis of his “good immunity” (high CD4, low viral load); he evaluates his doctor positively partly on the basis of the quality of the conversation they have in his “five minute” consultations.

My intention here is not to claim that clients “lie” to their doctors while citizens do not. It is to merely point out that any determination of what is “sayable” between doctors and patients, and the perceived costs of communicating certain information, is influenced, on the patient’s part, by her/his fundamental orientation to the interaction. Divergent understandings of access to care, whether based on rights, or on the favor or discretion of a more powerful entity, can result in potentially different priorities (informing vs. pleasing the doctor).

Hence, Renato did not tell his doctor that he and Milene do not use condoms. As far as Renato was concerned, because of his undetectable viral load, he was incapable of transmitting HIV to his wife anyway. But because he and his doctor did not have a conversation about these issues, the couple did not even entertain modifying their sexual practice during the initial period of Renato’s latest troca, which, biomedically speaking, constituted a time of potentially greater infectiousness (especially in a patient like Renato, who had started and stopped a couple of different ARV regimens; lack of resistance to new medications cannot be assumed). Thus, silence on the part of both the doctor and the patient led to a situation in which sub-optimal treatment was provided, if we consider Renato as a whole person. While seroconversion may truly make little difference to Milene, both she and Renato acknowledge it would have a serious, negative psychological impact on him.

I have no proof that, had he engaged with his HIV treatment from a rights-based perspective, Renato would have been honest with his physician about condom use with his partner, or that it would have made any difference to his doctor if he had. Likewise, I understand
that Renato’s is just one case, and an N of 1 means little in and of itself. However, because, to my knowledge, this situation unfolded as described above, it is possible that these dynamics are at work more generally. Such differences in patient orientation may be thwarting the best intentions of clinicians to provide excellent HIV care, and reducing the effectiveness of the concessions to adherence patients are willing to make.

Returning to the research questions, overall, in juxtaposition to the way they are frequently portrayed in the academic literature, neither HIV, nor the risk of contracting the virus, nor the concept of “serodiscordance” itself, are monolithic in their meaning. Rather, they are contingent and cannot be understood in isolation from either the parameters of Brazilian couplehood or the larger social context in which they occur. However, an overarching generalization on the basis of the data are defensible: the lack of BMMC among this sample, like the presence of the discourse of normality and the semantic quarantine, can be explained, in part, as a reaction to the prevalence of HIV/AIDS-related stigma in Porto Alegre. For these HIV-serodiscordant couples, it is what people think about the virus, rather than the effects of the virus itself, that occupies the most space in their daily lives, and structures their interactions with each other and wider society.

**Recommendations**

**Explanation of Targeting**

The prominence of HIV/AIDS-related stigma in the findings from this research was somewhat surprising, since Brazil has taken notable action in two main areas believed to diminish such attitudes: providing treatment and disseminating biomedically accurate information. Based on findings from both Haiti and Brazil, researchers have suggested that the availability of treatment for HIV/AIDS reduces stigma (Castro and Farmer 2005; Abadía-Barrero
and Castro 2006); as demonstrated in this research—at least for this small group of seropositives—treatment is available and effective. Stigma is also said to be “based on misinformation and ignorance about disease transmission” (Land and Linsk 2013:3; see also Brown, Macintyre and Trujillo 2003). Brazil has mounted national media campaigns designed to raise awareness about HIV/AIDS since 1992 (PN-DST/Aids 2007a). In fact, combatting stigma around HIV-serodiscordant relationship was even the subject of a fairly visible example during the period of fieldwork for this dissertation.\(^{120}\)

Unfortunately, as Neema (2012:232) notes, “Despite extensive knowledge regarding the consequences of stigma and discrimination, comparatively little progress has been made in systematically addressing these in public health programs.” Part of the issue is the difficulty in evaluating stigma reduction interventions (in real vs. simulated interactions, over time, etc.). Nonetheless, some, including those utilizing mass communication techniques (e.g., Peltzer et al. 2012:1), have been shown to be effective; personal interaction with a PLWHA seems to enhance results (see Brown, Macintyre and Trujillo 2003:62).

The problem with enlisting PLWHA as “faces” of AIDS is that this approach relies on the individuals most in need of protection from noxious social dynamics in the effort to change the status quo. While some seropositive individuals selflessly (and helpfully) participate in such efforts, the ethical principle of respect for persons (autonomy), as well as a concern with non-maleficence, should lead researchers to conclude that this strand of GIPA (“Greater Involvement of People with AIDS,” discussed at length in Nguyen 2010) cannot ethically be framed as the basis for stigma eradication.

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\(^{120}\) A media campaign featured a man and a woman kissing with the caption, “One of them has HIV. The other knows. It’s possible to live with HIV, but not with stigma/discrimination.”
Hence, the recommendations stemming from this research are directed toward reducing stigma through channels that do not rely on PLWHA to expose themselves to possible harm.

**Specific Recommendations**

The broad recommendation made here is to use stories in various formats to increase exposure to, and even simulate a personal relationship with PLWHA. First and foremost, television is an exceedingly influential medium in Brazil (Skidmore 1999; Machado-Borges 2003). Although at least one popular Brazilian telenovela, Malhação, has featured an HIV-positive character and dealt with adherence to ARVs, more should be done. Specifically, story lines for HIV-positive characters should not revolve solely around their serostatus, but portray them as whole human beings with a full complement of joys and worries. This not only reflects the reality lived by most of the seropositive patients I spoke to during this research, it also, following the theory of discourse utilized in this dissertation, should begin to shape Discourse about HIV/AIDS among the viewing public.

This experience of “getting to know” a seropositive person/character could be enhanced through interactivity. Brazilians have demonstrated their willingness to engage in this type of interaction, for example, via text message voting linked to “reality” television shows like Big Brother Brasil. Efforts to reduce HIV/AIDS-related stigma could capitalize on this trend. For example, Globo (the channel with the largest viewership of evening telenovelas) and the DDST/Aids/HV could team up to create a realistic story line for a seropositive main character. Then that character could be linked to a social networking page/profile viewers could “friend,” and a text messaging service to which they could subscribe. Ideally, the Federal government would subsidize this program, allowing even Brazilians from the classe popular to participate (as

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noted in this dissertation, all of my participants had cellular telephones; text messaging was often less expensive than actually talking).

The social networking approach allows the use of video and photographs to enhance the feeling of personal connection, as well as quicker, “sexier” dissemination of HIV prevention materials. The text messaging service could blend information about the telenovela with facts about HIV (biomedical and epidemiological). Parts of the service could even be designed as trivia questions that, if answered correctly, would “win” the subscriber previews or hints about upcoming plot twists, for example (indeed, anything one cares about—say, particular soccer teams—could be enlisted for similar programs).

Additional venues for story-telling approaches abound. For example, the newspaper Zero Hora sponsored a media campaign during the course of this fieldwork dealing with the “epidemic” of crack addiction that was affecting the city.\footnote{Posters, T-shirts and pages in the newspaper itself featured white, block letters on a black background that said: “Crack: Nem Pensar” (Crack: Don’t Even Think About It).} Given Porto Alegre’s unenviable status as the indisputed leader among Brazilian municipalities in terms of AIDS incidence, the newspaper could, working with either the State Health Secretariat or the City Health Department, publish a series of stories on factors contributing to transmission, and the daily lives of seropositive people (who could remain anonymous). Although other newspapers in the city did not appear to engage in the same kind of investigative journalism Zero Hora produced, biographical sketches designed to erode the notion of seropositive people as “Other” would not require the investment of significant resources, particularly if created in consultation with policy makers, health professionals, and civil society groups. While some might characterize these as unrealistic, inappropriate “First World” solutions, I would suggest that Brazil, in the realm of
AIDS, already has a fairly impressive track record with such “impossible” policies. It would not hurt to try again.

**Dissemination of Results**

Results of this research have been orally disseminated in several venues since my return from the field in July of 2010. In addition to guest lectures in two USF Anthropology classes, I presented the paper “Re-Imagining Love and Risk: HIV Serodiscordant Couples in Porto Alegre, Brazil” at the 2011 meeting of the American Anthropological Association (AAA) in Montreal, Quebec, CA. I also presented my paper “Of Resources and Rights in Porto Alegre, Brazil: Patient Citizenship or Just the *Jeito*?” at the 2013 meeting of the Society for Applied Anthropology (SfAA) in Denver, CO.

Plans for future dissemination of these results, as a matter of research ethics, include making them available to the participants, both key informants and members of the serodiscordant couples, when possible. One way I envision achieving this is to create a short video to post on the Internet in which I summarize my findings in accessible language. Using contact information I currently have, the web address for the video can be communicated via text message (a preferred mode of communication amongst the members of serodiscordant couples), email, social networking sites (including Orkut, which is immensely popular in Brazil), telephone, and post. Further, a written summary of results will be sent to the directors of both the hospital department and the clinic where I observed and recruited for the serodiscordant couples component of this project. Given the effectiveness of vignettes as a data collection tool, I am contemplating their use to disseminate findings as well. This format—short, but packed with relevant ethnographic detail—could help public health and biomedical professionals better understand the populations they attempt to reach and treat. The video and the written summaries
will be in Portuguese. Finally, both the “Documentation Center” at the hospital and Porto Alegre’s municipal health department will also be provided with copies of the final (English) version of this dissertation (in accordance with CEP regulations).

Other strategies target academic audiences. At the urging of my advisor, I have already conceptualized particular pieces of this dissertation as articles to be submitted to peer-reviewed journals, such as Medical Anthropology; Medical Anthropology Quarterly; Social Science & Medicine; Signs: Journal of Women in Culture and Society; Culture, Health, and Sexuality; AIDS Care; Field Methods; and the Brazilian journals *Cadernos de Saúde Pública* and *Horizontes Antropológicos*. Further, Asha Persson has suggested co-planning a symposium on serodiscordance for the 20th International AIDS Conference (AIDS 2014) in Melbourne, Australia, in July 2014. Last, but certainly not least, I hope to publish some version of this dissertation as a monograph through an academic press.

**Future Research**

A sample of six couples was sufficient for this exploratory study, in a context where HIV-serodiscordant couples were largely an unknown population. Indeed, I believe limited but important assessments of “transferability” (Guba 1981) to new contexts by readers can be made on the basis of the data reported here. However, in order to put these findings to work, similar work conducted with more couples is necessary. Ideally, this would occur both in Porto Alegre and in other, culturally distinct, places. This comparative approach will be particularly important in the wake of the FDA’s approval of Truvada for the prevention of HIV in certain populations (including within serodiscordant partnerships), and the Brazilian Ministry of Health’s subsequent decision not to implement such a policy.
In addition, as discussed in Chapter 4, the inability to include populations who lack or have only tenuous access to the public health system in Brazil restricted my ability to study iterations of risk as opportunity or commodity. With a hypothesis regarding what one might call a class-based “ceiling” on such constructions, future research can be designed (for example, with different locales and strategies for recruitment) to better address these questions.

Reflections

The heartbreak of holding the view that social reality is largely the effect of discourse is inescapable when considering the data reported in this dissertation. Every word, every action, every identity comes to us, weighted by history, inflected by others. As we are dependent upon those others for recognition, meanings are only partially amenable to our reinterpretations. Because there is no place outside of systems of power and meaning from which to speak, even dissent from those regimes, as seen, for example, in the discourse of normality, reinstates that which we are attempting to destabilize.

Many utterances already cited in this dissertation reveal, in the context of conjugal relationships, the current incommensurability of HIV/AIDS with the life research participants want (a sexual life, a normal life). There is, nevertheless, hope to be found in the discursive approach to social life taken in this dissertation. Because discourse simultaneously conjures the reality it names, naming is a powerful, constitutive act. Each time speakers stake a discursive claim to “a normal life,” they effect a counter-hegemonic aggregation, placing seropositivity and normality in the same category. Thus, while I have analyzed the discourse of normality, the semantic quarantine, and the refusal of biomedically mediated forms of citizenship as accommodations to and defenses against AIDS-related stigma, they are also, simultaneously,
revolutionary acts. Over time, through repetition, performed by bodies that are visually indistinguishable from HIV-seronegative bodies, a new reality can acquire material form.

Further, we will be able to identify when we have reached this tipping point. A close attention to discourse will reveal the completion of sentences formerly left unfinished, and the greater cohesion of narratives that bring together elements of life, and love, and sex, and HIV. But attending to discourse will also reveal new silences, particularly about “normal life.” HIV serodiscordant couples will cease talking about their lives in these terms. It will be unnecessary for them to tell us, the interlocutors upon whom they depend for recognition, that they are “normal people” leading “normal lives.” We will already know.
Appendix I: Abbreviations/Translations

AIDS: Acquired Immune Deficiency Syndrome

ARV: Anti-retroviral Treatment

AZT: Azidothymidine, a particular ARV used to prevent MTCT

BMMC: Biomedically-Mediated Citizenship, intended to encompass various approaches to health-related forms of citizenship found in the academic literature (for example, biological citizenship, patient-citizenship, health citizenship, therapeutic citizenship)

CEP: Comité de Ética em Pesquisa, Research Ethics Committee

CES: Conselho Estadual de Saúde, State Health Council

CGVS: Coordenadoria Geral de Vigilância da Saúde-Porto Alegre, municipal health surveillance office in Porto Alegre

CMS: Conselho Municipal de Saúde, or City Health Council

COAS: Centro de Orientação e Apoio Sorológica, [HIV] Testing and Counseling Center

CSW: Commercial Sex Worker

DDST/Aids/HV: Departamento de DST/Aids e Hepatites Virais, Department of STDs/AIDS and Viral Hepatitis (formerly the PN-DST/AIDS)

ED: Emergency Department/Urgent Care

ESF: Estratégia Saúde da Família, Family Health Strategy (formerly PSF: Programa Saúde da Família)

FGTS: Fundo de Garantia por Tempo de Servico, a type of obligatory savings account for those in the formal labor market that can be accessed to the worker on the basis of HIV/AIDS

HAART: Highly-Active Anti-retroviral Treatment

HepC: Hepatitis C

HIV: Human Immunodeficiency Virus
IBGE: Instituto Brasileiro de Geografia e Estatística, the Brazilian Institute of Geography and Statistics

IDU: Injection Drug Use/User

MSM: Men who have Sex with Men

MTCT: Mother-To-Child Transmission

NOAS-SUS: Normas Operacionais de Assistência, one iteration of the formal rules assigning particular responsibilities vis-à-vis the health care system to specific levels of government (municipal, state, or Federal)

PN-DST/AIDS: Programa Nacional das DST/AIDS, the National Program for STDs and HIV/AIDS

PT: Partido dos Trabalhadores, Workers’ Party

RS: Rio Grande do Sul, the Brazilian state where fieldwork was conducted

SAE: Serviço de Atendimento (or Assistência) Especializado em DST/Aids, Specialized Treatment Clinic for STDs/AIDS

SES: Secretaria Estadual de Saúde, State Health Department

SINAN: Brazil’s national database of disease notification

SISCEL: Brazil’s national surveillance system for lab results on CD4 counts and viral loads

SICLOM: Brazil’s accounting system for antiretroviral medication

SMS: Secretaria Municipal de Saúde, City Health Department

SUS: Sistema Único da Saúde, the Brazilian (public) health care system

TCLE: Termo de Consentimento Livre e Esclarecido, informed consent document for human subjects research

TRI: “smart” card used for pre-paying fares on buses within Porto Alegre

UAI: Unprotected Anal Intercourse

UBS: Unidade Básica de Saúde, or Basic Health Unit. A particular kind of neighborhood clinic offering primary care through SUS

WTO: World Trade Organization
Appendix II: Vignettes

Instruções para as vinhetas: Por favor, escute e depois responda às perguntas sobre esta situação hipotética:

Vinheta 1: Maria e André se conheceram numa festa de aniversário duma prima da Maria; estão juntos há um ano. Souberam há três semanas que Maria está grávida. Como parte da rotina de pre-natal, o médico pediu um teste HIV e a Maria agora recebe o resultado: ela é HIV-positiva.

Perguntas: Como você acha que a Maria está se sentindo neste momento?
O que deve fazer a Maria?
Como vai se sentir o André quando ele souber do resultado?
O que deve fazer o André?
O que vai acontecer com Maria e André?
Como pode ter acontecido tal situação?

Vinheta 2: Marcela se apaixonou por Miguel aos 18 anos, mas os pais dela não gostavam dele e proibiram o namoro. Ela resolveu sair da casa dos pais dela para morar com ele, já que ele era caminhoneiro, ganhava bem e tinha casa própria. Mas seis meses depois deles ficarem juntos, ele começou a bater nela. Ela fugiu, mas os pais dela não a aceitaram de volta em casa e ela ficou com uma amiga que era guria de programa. Como não achava outro emprego, Marcela começou a trabalhar com essa amiga. Depois de cinco meses ficou doente. O médico pediu um teste HIV e o resultado deu positivo.

Perguntas: O que você acha que a Marcela está se sentindo neste momento?
O que ela deve fazer?
Como pode ter acontecido esta situação?
O que vai acontecer com a Marcela?

Vinheta 3: Roberto era um pai de família bem-sucedido, mas um dia descobriu que a linda esposa e o melhor amigo dele tinham um caso. Ela pediu a separação depois de 12 anos de casamento e levou os dois filhos pequenos com ela. Roberto começou a sair na noite com outros amigos dele. Nunca quis ficar com as mulheres que ele conheceu nos bares, mas o mais comum era ele beber—e beber muito. Aconteceu às vezes ele acordar, de manhã, sem saber como chegou em casa. Isso lhe deu medo e ele conseguiu parar. Depois ele conheceu a Raquel, que virou a nova mulher da sua vida. Antes de terem a primeira relação sexual, os dois fizeram o teste, e Roberto recebe o resultado dele primeiro: é positivo.

Perguntas: O que você acha que Roberto está se sentindo neste momento?
O que ele deve fazer?
Quando a Raquel souber, como vai reagir?
O que deve fazer a Raquel?
Como pode ter acontecido esta situação?
O que vai acontecer com a Roberto e Raquel?
Appendix III: Map of Brazil

Reservas.net: [http://www.reservas.net/alojamiento_hoteles/portoalegre_mapasplanos.htm](http://www.reservas.net/alojamiento_hoteles/portoalegre_mapasplanos.htm), accessed March 9, 2013
Appendix IV: Stigma at the Clinic

Introduction

Throughout this dissertation, I have reported on observations at the clinic where recruitment of seropositive members of HIV-serodiscordant couples took place, and discussed interviews with biomedical practitioners (see Chapters 1, 2, 5 and 7). However, here I report, in a consolidated and systematic way, data gathered using those methods that directly pertain to the notion of stigma. There are various kinds of stigma, including perceived, enacted, self, and secondary, but all are inherently social (in that they stem from collectively-held beliefs and values), and can have deleterious consequences for health (Goffman 1963; Brown, Macintyre, and Trujillo 2003; Neema et al. 2012; Land and Linsk 2013). In that the clinic is the primary space where HIV-positive participants in this study are exposed to biomedical discourse about the virus and how to live with it, examining what goes on in that context for its relation to stigma is important. Such data are significant in their own right (in-depth analysis is planned in the near future), but here they serve to contextualize the main findings reported in the dissertation, which deal with the perspectives and experiences of serodiscordant couples. It bears noting that in no case (during observations and informal interviews with clinic patients and staff; during formal interviews with clinic staff; during data collection activities with serodiscordant couples) did I raise the issue of stigma; this topic was always spontaneously mentioned by participants first. Data from observations and interviews are presented separately.

123 Although data collected during the institutional mapping component of this study could shed light on the prevalence of stigma in Porto Alegre more generally, HIV-serodiscordant couples in this sample were not engaged with health activism or policymaking at the state or municipal level, and were not even aware of AIDS-related NGOs. Hence, the focus here is on clinic-level work.
Observations

As reported in Chapter 4, the most intensive clinic-level observations took place from late August-December 2009. In the interest of parsimony, here I present results from a two-week sample, in which observations were conducted on 7 out of 10 days. Different modalities of observation were employed during these sessions (e.g., waiting area- and practitioner-based), and the degree to which I had the opportunity to interact with patients varied. Nonetheless, fieldnotes document 30 separate, substantive interactions with patients (the longest around an hour in duration). Stigma figured in 14 of those 30 occasions.

Total Mentions of Stigma

<table>
<thead>
<tr>
<th>Stigma mentioned by</th>
<th>Waiting Area-based Observations</th>
<th>Practitioner-based Observations</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>10</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Practitioner</td>
<td>0</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>

Waiting-area Based Observations

The majority of data regarding stigma in this sample was collected during informal interviews with patients in the waiting area. All of the longest interactions with patients occurred in this format. The types of stigma manifested varied. Secondary stigma was exemplified by the male respondent in his mid-40s who noted that his girlfriend hates to come to the clinic because she doesn’t want to be seen there (observations, 31 August 2009). A female patient in a flowered dress provided an early example of the discourse of normality when she said, “Where I live, everyone knows [about my serostatus], and they treat me like a normal person” (observations, 27 August 2009). This is an indirect reference to perceived (and/or perhaps self) stigma, since this type of treatment is seen as worth commenting upon. In addition, as was the case with similar comments made by members of serodiscordant couples, the implicit point of reference is clearly seronegativity. Another female patient told a story about enacted stigma; she
reported feeling “judged” by her physician, so she switched providers (observations, 3 September 2009).

Potentially the most striking example recorded during the observations contained in this sample came from a female patient whom I’ll call Nina. Her clothing and overall appearance differentiated her from most of the other patients. Her posture, seated, with arms crossed, head down, and sunglasses on, accentuated this impression. Though our conversation was halting at first, she began to open up as she waited to be seen by her doctor. One of the first comments she volunteered had to do with stigma. She noted that this was still prevalent, and continued, “Even among us [seropositive people]. Like me, I have a ton of stigma. You notice I don’t take my sunglasses off,” implying her desire to be shielded from recognition, as well as to erect a barrier between herself and those around her.

Although the conversation ranged across many topics, Nina returned to stigma twice more before inviting me to observe her consult with the physician. In both instances, stigma was cited as the reason for a lack of disclosure of her serostatus (in six years she had told only two close friends, but no one in her family). For example, she explained that in the course of everyday conversation with friends, “[Someone] will say, ‘Did you hear? So and so has AIDS.’ Like that: ‘AIDS’ (in a hushed, disgusted tone). It’s not the same as saying s/he got cancer.” Later she continued, “There’s this idea that AIDS used to be a gay thing—and then prostitutes. So if you have it, there’s this, ‘Oh, how many [men did you sleep with]?’ I feel that judgment” (observations, 24 August 2009).

Practitioner-based Observations

Far fewer examples of stigma-related observations came from practitioner-based observations. In part, this may have been due to the type of appointments observed during this
time period; routine check-ups and problem-oriented consultations predominated. Much patient and practitioner talk was therefore either brief or highly focused. Nonetheless, the four examples are interesting for their variety. One case serves to triangulate other data, and lend further credence to the interpretation that stigma is a primary concern of clinic patients. This practitioner responded to my question about the most common complaints she sees in her work by saying that she doesn’t receive “complaints” so much as the patients need someone to talk to about stigma. She reported a current surge in claims that seropositive people had lost their jobs due to discriminatory practices (observations, 4 September 2009).

Another case demonstrated how provider awareness of, and willingness to deal with AIDS-related stigma can benefit patients. During an appointment in the ambulatório de adesão (see Chapter 2 for more details on this type of appointment), a recently-diagnosed, middle-aged woman was asked what her greatest fear about her diagnosis was. She answered tearfully that she’d heard even a cold would now constitute a risk to her life. The practitioner responded with a reassuring smile as she said, “The biggest problems of HIV-positive people today are misinformation and stigma. You’ll see today that HIV is just like any chronic disease” (observations, 2 September 2009). Then she proceeded to use the patient’s high blood pressure (which was being controlled through medication) as an example, to the patient’s evident relief.

Other data suggest greater complexity at play. While I never observed a provider propagate AIDS-specific stigma, they did sometimes react to situations that arose in the course of their work in ways that seemed to reinforce the stigmatization of other identities and practices with which conceptions of AIDS are enmeshed, especially poverty and sexuality. One practitioner commented to me, “They just don’t take care of themselves, you know? It’s incredible” (observations, 28 August 2009). This reaction may be an understandable defense
mechanism among those responsible for treating poor patients who confront many structural obstacles to adherence. But in essentializing patients as uninterested in or incapable of understanding the dictates of biomedicine—that is, as unsanitary subjects—it also removes any impetus for providers to investigate reasons for non-adherent behaviors, or to find ways to work around specific challenges patients face.

I learned of another example of the way stigma can diminish quality of care days after it occurred. A female patient, upon receiving her allotment of male condoms and lubricating gel, asked to speak to a female practitioner in private. Once the two were alone, the patient explained that her husband wanted to engage in anal intercourse; she asked for guidance on how to use the gel. The practitioner reported telling the woman to apply the gel to the condom. “And then? Can you also—?” the patient began, but the practitioner interrupted, “Hold on! I don’t know! If your husband is wanting this, you should ask him. He must have some experience with it.” This story was told to peals of laughter from several staff members. The power of the taboo on anal sex for “good” women in this case precluded not just instruction in techniques designed to minimize the likelihood of HIV transmission, but also any opportunity for discussion about the patient’s own sexual desires and fulfillment.

Interviews

The data reported in this section are drawn from the six interviews conducted with biomedical practitioners who work at the clinic. They represent a variety of medical specialties; to safeguard their anonymity, I refer to them only by number (omitting gender, titles, and other potentially identifying details). Although stigma was not a topic covered in the semi-structured interview guide used with these practitioners, it arose spontaneously, albeit in various ways, in all the interviews. Some of these narratives must go unreported because the details make it
impossible to disguise the identity of the speaker without fundamentally compromising the data; others have been slightly modified. Overall, these interviews support the already strong argument that stigma is a prominent concern among patients, and that it has negative consequences on health. Most providers are aware that AIDS-specific stigma is intertwined with other forms; some feel able, and attempt to help patients confront this, others do not.

Exemplary Stigma Related Comments

<table>
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<th>Interviewee</th>
<th>Interview Date</th>
<th>Notable comments on stigma</th>
</tr>
</thead>
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<tr>
<td>Practitioner #1</td>
<td>29 April 2009</td>
<td>Family’s reaction to workplace location; interrelated stigmas</td>
</tr>
<tr>
<td>Practitioner #2</td>
<td>24 August 2009</td>
<td>Influence on clinic location</td>
</tr>
<tr>
<td>Practitioner #3</td>
<td>21 September 2009</td>
<td>Respect triggers adherence</td>
</tr>
<tr>
<td>Practitioner #4</td>
<td>2 December 2009</td>
<td>Living conditions vs. understanding treatment</td>
</tr>
<tr>
<td>Practitioner #5</td>
<td>11 December 2009</td>
<td>Living conditions distinct from understanding about treatment; adherence among poor</td>
</tr>
<tr>
<td>Practitioner #6</td>
<td>27 April 2010</td>
<td>No one wants to work with HIV; greatest need of patients</td>
</tr>
</tbody>
</table>

Stigma, both AIDS-related and linked to poverty and sexuality, surfaced in practitioner interviews in various ways. Sometimes it was a force that impacted the health of individual patients; sometimes its effects manifested more structurally. Only one interviewee did not specifically address the issue of AIDS-related preconceito (stigma); yet stigma remained relevant to interpreting statements from this interview. His/her explanation of the challenges to adherence faced by patients drew directly from essentializing and stigmatized characterizations of the classe popular, in a way reminiscent of the practitioner mentioned in the previous section, who generalized patients as not “tak[ing] care of” themselves. Although most interviewees linked conditions of poverty and marginalization to difficulties in treatment adherence, the relationship understood to pertain between these phenomena varied.
Stigma at Structural Levels

As explained in Chapter 2, the clinic had undergone significant changes since its inception in 1996; many of the interviewees, as long-time staff, had experienced that evolution first-hand. They noted that not only had the clinic and the type of patients it treated changed, but perceptions of stigma had altered over time as well. Practitioner (hereafter abbreviated “P”) #2 acknowledged that AIDS-related stigma had been stronger at that time of the clinic’s founding than when this research was conducted. S/he claimed that it was partially because of preconceito that the clinic was the sole thing located on the first floor at the time of its inauguration. It was only after the efficacy of ARVs was fully apparent, in 2002, that the UBS was installed.

Although one interviewee (P#4) explicitly disavowed knowledge of any colleagues that still hesitated to treat HIV-positive patients, P#1 asserted that AIDS-related stigma was still easy to find among healthcare workers, and that it was related to class- and sexuality-based types that also persisted, despite attempts at consciousness-raising. Most practitioners appeared to agree with P#6, who said, “It’s very rare that someone volunteers to work [at the clinic], because no one wants to work with HIV, even today…because of stigma—fear of getting infected. They think that they’ll get the virus by touching someone with HIV, as incredible as that sounds.”

While by no means discounting this explanation, it must be acknowledged that AIDS-related stigma is not the only potentially dissuasive force limiting the pool of qualified personnel from which the clinic can draw. As previously explored (see Chapter 2), the clinic’s location in one of the city’s most well-known vilas must be considered. Biomedical practitioners, given the structure of Brazil’s post-secondary education system, tend to come from middle- and upper-class families (Stepan 2007); thus, they often have little experience with neighborhoods like the one containing the clinic. One interviewee noted that s/he had never set foot inside a vila before
beginning work at the clinic, and his/her family, worried about his/her safety, had advocated waiting for another post (P#1). Even when physical safety was not a concern, the security of one’s property—especially automobiles (all the physicians I knew at the clinic drove to work)—frequently was. Not all health professionals were willing to take the “risk” of working in a low-income area.

**Stigma at Interpersonal Levels**

All interviewees noted the pauperization of the epidemic, and most linked socioeconomic conditions to adherence difficulties experienced by patients. This was especially prominent in the interview with P#4. Although s/he never mentioned AIDS-related stigma, class-based stigma was implicit but unmistakable. For example, in enumerating the challenges faced by clinic patients, s/he initially commented on their “ignorance,” elaborating, “They have a very low educational level, you know? So it’s difficult for them to understand the treatment.” Specifically, the importance of taking all ARV doses on time “goes in one ear and out the other…because the rest of their life is so bad, you know? So HIV is the least of their problems. They don’t have anything to eat, anywhere to live, their child is a drug addict, their husband is in jail, the other child is hungry and there’s no food at home; the virus is the least of their worries.” S/he contrasts this with patients seen in his/her private practice; their biggest problem is the virus, so they adhere to their medicine.

When asked whether this explanation conflated two factors (living conditions and lack of understanding) that might be better understood separately, s/he claimed this is a cycle that can’t be broken. S/he continued, “It’s no use. I do the same thing here that I do in my private practice; [but] there (i.e., at his/her private office) I have to scold someone for not taking their medicine once or twice a month. [At the clinic] I scold two or three people a day. They don’t
understand what they’re dealing with in HIV.” P#4 acknowledged differences in employment opportunities and financial resources between these two groups of patients, including access to a healthy diet and opportunity to exercise as supplements to pharmacological treatment. And yet, s/he appeared to sincerely believe that “the same” actions on the part of the clinician should be sufficient in both cases. Further, when that proved not to be the case, s/he persisted in attributing this failure to a lack of understanding or interest on the part of poor and working-class patients. As noted in the previous section of this Appendix, this serves to remove the practitioner’s responsibility to account for social determinants of health.

While commentary on the material deprivation of the average clinic patient was universal among this sample, other interviewees positioned poverty differently in relation to adherence. One interviewee (P#5), when asked about the challenges faced by non-adherent patients answered with no hesitation: “Individual factors! For example, they don’t have work, or food, things like that. Not factors related to the disease, but those related to their [socioeconomic/personal] context. Of course.” Other practitioners offered still different, and more programmatic (Ayres et al. 2003, 2006), explanations. For example, P#3 also listed socioeconomic conditions and lack of education as problems faced by clinic patients, but then linked this to the inadequacy of the public health care system in Brazil. In essence, instead of positing poverty as something inherent that renders patients incapable of adherence, s/he foregrounded the inability of SUS to meet the health needs of low-income populations.

All of these constructions have in common their tendency to interpret “the poor” as de facto unsanitary subjects, demonstrating the prevalence of class-based stigma. There was important variation, however, among this sample in terms of their conception of the determinacy

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124 The question in each case was phrased in terms of “challenges patients face in adherence,” and was answered as though only low-income individuals confront such difficulties.
of class status in patients’ behavior. For example, in a story told by P#5, persistence and the provision of information were key to helping a long-time female patient, poor and suffering from drug addiction, to comply with her ARV regimen. Upon discovering this patient’s pregnancy, the practitioner supported the assumption of this woman’s new social role as a mother, seeing it as a chance to “start over.” S/he explained procedures to prevent MTCT in detail and repeatedly. As the interviewee concluded: “For whatever reason, [the patient] began to take her medicine, was able to bring her viral load under control, her baby is HIV-negative, and she continued to comply with treatment afterward.” Thus, while some practitioners (e.g., P#4) chose to highlight the lack of adherence among low-income patients, others (e.g., P#5) emphasized success stories.

Stories about stigma’s influence on the health of individual patients were not uncommon, and often included the imbrication of specifically AIDS-related varieties with the stigma of poverty. P#1, P#2, P#3, and P#6 made such comments. P#6 specifically described the most urgent need of seropositive patients in Porto Alegre as “to feel…equal to others, and they don’t feel this because of the stigma, you know?” P#3 emphasized the difference practitioners can make in helping impoverished, marginalized, seropositive individuals to overcome stigma and become model patients. In this narrative, a patient, “very poor—one of those, you know?—and an alcoholic…came [to the clinic]” because he was experiencing clinical problems, but his doctor was on vacation. After being seen by another physician, well-known for his expertise and diligence, the patient announced, “I will never go back to [my old doctor]; she never touched me, never. The appointment was always over in a minute.” In contrast, this physician had not only given him a thorough physical examination, but had asked whether the patient’s wife were also seropositive, using the polite phrasing, “E sua senhora tem o virus?” The patient, in telling this story to my interviewee (who subsequently recounted it for me), shook his head, saying, “[The
doctor] called her my ‘senhora.’ The whole world treats me like an animal, you know?...here I was treated with respect.” The patient started taking his ARVs consistently and never stopped; his viral load fell to an undetectable level.

Overall, data from interviews with clinic practitioners suggest that there is significant awareness of the impact of stigma, both specifically AIDS-related and more general, on the health of patients, and even the functioning of the clinic itself. Although all interviewees explicitly dissented from stigmatizing constructions of HIV/AIDS, manifestations of other types of stigma (especially those linked to poverty and non-heterosexuality) among this sample ranged from acceptance and propagation, to problematization, to rejection. Practitioners who did not question, for example, class-based stigma were most likely to essentialize impoverished patients as incapable of or uninterested in adherence to biomedical prescriptions regarding appropriate ways to live with HIV.

Conclusion

This appendix provided a consolidated and focused report on data collection activities (observations and interviews with biomedical practitioners) conducted at the clinic where recruitment for the principal component of this research took place. Specifically, data on stigma served to contextualize the findings from HIV-serodiscordant couples reported in the body of the dissertation. The perception of stigma’s prevalence, reported by all serodiscordant couples, was confirmed by frequent and spontaneous mentions on the part of both patients and providers in the therapeutic context. Further, results from clinic-level work revealed the presence of various kinds of stigma, including perceived, enacted, self, and secondary (Goffman 1963; Brown, Macintyre, and Trujillo 2003; Neema et al. 2012; Land and Linsk 2013), related not only to AIDS but also class and sexuality. Findings also attested to various avenues through which stigma can
negatively impact patients’ health. Outside the clinic, patients reported managing stigma largely through selective disclosure (a practice common among participants in the couples component of this research as well); inside the clinic, perceived negative judgments by providers prompted four patients to terminate that particular clinical relationship. Among providers, while AIDS-related stigma was rejected by all, other types were observed to sometimes affect interactions with patients. Stigmatizing constructions of non-normative sexual practices, and of the popular- and working-classes were observed to negatively impact the provision of care.
Appendix V: IRB Approval

January 2, 2009

Shana Hughes
Anthropology
1901 S. Ridgewood
Wichita, KS 67218

RE: Expedited Approval for Initial Review
IRB#: 107520 G
Title: Risk as Social Process: HIV-Serodiscordant Couples and Biomedical Practitioners in Porto Alegre, Brazil
Study Approval Period: 12/20/2008 to 12/29/2009

Dear Ms. Hughes:

On December 30, 2008, Institutional Review Board (IRB) reviewed and APPROVED the above protocol for the period indicated above. It was the determination of the IRB that your study qualified for expedited review based on the federal expedited category number six (6) and seven (7).

Also, approved with English and Spanish adult informed consent forms.

Please note, if applicable, the enclosed informed consent/assent documents are valid during the period indicated by the official, IRB-Approval stamp located on page one of the form. Valid consent must be documented on a copy of the most recently IRB-approved consent form. Make copies from the enclosed original.

Please reference the above IRB protocol number in all correspondence regarding this protocol with the IRB or the Division of Research Integrity and Compliance. In addition, we have enclosed an Institutional Review Board (IRB) Quick Reference Guide providing guidelines and resources to assist you in meeting your responsibilities in the conduction of human participant research. Please read this guide carefully. It is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB.
We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-9343.

Sincerely,

Krista Kutash, Ph.D., Chairperson
USF Institutional Review Board

Enclosures: (If applicable) IRB-Approved, Stamped Informed Consent/Assent Documents(s)

Cc: Anna Davis/ed, USF IRB Professional Staff
Linda Whiteford, PhD

SB-IRB-Approved-EXPEDITED-0801
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