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Chronic/Life Threatening Illnesses From the Perspective of Latino Men

by

Melissa Sierra

A thesis submitted in partial fulfillment
of the requirements for the degree of
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Department of Sociology
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University of South Florida

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Dedication

This study is dedicated to my research participants for sharing their experiences and teaching me so much about their lives. Thank you for enlightening me about the important connections between culture and illness.

Acknowledgments

I would like to thank Dr. Jennifer Friedman for all of her help and support. She means more to me than she could ever imagine. She took me under her wing and educated me, not only about Sociology and my study, but also about life and about myself. She helped me have confidence in myself at a time when I just wanted to give up. Because of her, I feel confident about myself and believe that no matter what anyone thinks, I am able to achieve many things. I want to give thanks to Dr. Sara Green and Dr. Laurel Graham for their help in developing this study. They really came through for me no matter how busy they were and for that I thank them.

I would like to thank two very special people in my life, my two best friends, my mother (Andrea Sierra) and my father (Nelson Sierra). They have both been a great help as well as a wonderful support system. They have taught me that being an educated Latina will get me far in life and will help me to live an independent and positive life. My father is my inspiration for writing this study. I thank Jehovah God everyday for all of his blessings and for my father being alive. Throughout this whole experience, I gained an appreciation for my mother's strength and endurance. I only hope that during hard times I will be able to be as strong as her. Her strength is precious and powerful. Thank you mami, I love you. To Doreen, my wonderful sister, thanks for always believing in me and telling me that I CAN DO IT. I love you. To my brother Nelson, thanks for always looking up to me and having great pride that I am your sister. I love you very much. Finally, I would like to thank all of my family and friends for their love and support.

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Chronic/Life Threatening Illnesses From the Perspective of Latino Men

Melissa Sierra

ABSTRACT

Much of the research on illness focuses on how people, particularly white men, cope with chronic/life threatening illnesses often adopting a “sick role” identity. For Latinos this type of identity transformation is complex as there is no place for dependency and passivity in traditional depictions of Latino masculinity. Latino men take pride in their manhood. As a result, they have trouble accepting their illness and the sick role. They do not tend to take their illness seriously, nor are they comfortable admitting to others the seriousness of their illness. My research focuses on how Latino men renegotiate a sense of masculinity that provides more variation in how they enact their roles as men. The four Latino men I interviewed are all battling chronic/life threatening illnesses.

The concept of gender work provides a theoretical tool for analyzing the various identity transformations experienced during a long-term chronic/life illness. Although this concept has been typically applied to women and how they reenact a vision of femininity through daily work and interaction, it becomes useful for seeing how Latino men must renegotiate their masculinity which is one of the most fundamental parts of their senses of self. They redefine even the smallest tasks, ones typically defined as female oriented as a sense of masculine pride and accomplishment. Although these men’s illnesses have meant major compromises in their traditional vision of masculinity, the men with whom I spoke demonstrate the creative and social processes involved in doing gender.

Chapter One

Introduction

“I am now permanently disabled. I can’t win. I’m tired of being sick.”

Nelson

At the age of 12 I did not expect my father, Nelson, to tell my family and me that he had a life threatening disease called Chronic Myeloid Leukemia (CML). CML is a type of cancer of the blood, where the bone marrow is producing an extreme amount of white blood cells, killing off red blood cells and platelets. Even at the early age of 12, I understood that Leukemia was Cancer and that Cancer was a frightening word. I assumed that everyone with cancer just suffered and died. I feared losing my father who was only 32 years old at the time of his diagnosis in 1993. Three months later after being diagnosed with CML, my father had a bone marrow transplant. After a long recovery, he went into remission and began the process of rebuilding his life. I have become keenly interested in Latino men’s experience of chronic/life threatening illnesses as a result of my father’s experience¹.

Much of the research on illness focuses on how people, particularly white men, cope with chronic/life threatening illnesses often adopting a “sick role” identity. The sick role identity occurs when people become passive and expect others to take care of them. They tend to relinquish their roles as fathers, husbands, employees, and adopt identities as patients (Mirandé 1997, Abalos 2002, and The 2004). This type of identity

¹Chronic illness in this study is defined as “No longer illnesses to *die of*, but still not thoroughly curable, they have become illnesses to *lie with*. As more and more people learn to live hopefully and purposefully with the daily awareness of interminable disease, popular notions about the experience of illness are necessarily challenged” (Register 1999:xv).

transformation is complex for Latinos, as there is no place for dependency and passivity in traditional depictions of Latino masculinity.

For this research I am interested in how Latino men who are all battling a chronic/life threatening illness renegotiate a sense of masculinity that provides more variation in how they enact their roles as men. Such a shift in masculinity is best studied in men who have a well-established gender role, who are in their late 20s or 30s, and who experience a sudden change in their identity. This age bracket is unique for studying chronic/life-threatening illnesses because society expects for people who are older to be sick, not for people in their early 20s and 30s to be sick. These men as well, thought they would have to battle illnesses later in their lives, they never imagined that they would be sick in their 20s and 30s. The four Latino men I interviewed are all battling chronic/life threatening illnesses. These men experience continuous identity transformations, which require recreations of their masculine roles in relation to family members, to the larger medical and social service community, as well as to themselves. Identity transformations are continual because the disease constantly brings changes that require more transformations. Such an illness is not like a typical battle that can be fought and won as Nelson tells us in the above epigraph. It is a never-ending battle that touches every part of one's body and transforms how one thinks about himself and in particular about his manhood.

Although we live in the twenty first century, many males still believe that they should be the head of household (Abalos 1993 and Anaya 1996). Such a cultural ideal is especially pronounced and emphasized in the Latino working class family (Moore and Pachon 1985, Abalos 1993, Anaya 1996, and Ramírez 1999). It is not unusual for men to

insist on being “man of the house” and to refuse to allow wives to be the main financial provider. Yet, such a desire eventually gets compromised as people with chronic/life threatening illness become seriously ill. Although the sociological illness literature discusses at length that many chronically and terminally ill people have major identity transitions, no one seems to specify the various kinds of transitions that occur.

Focusing on Latino working class² men who have been socialized into a very strong image of masculinity, it is clear why their experience with illness would be different than other race, class, and gender groups. As one of the largest population groups in the U.S. (Vázquez and Torres 2003, Gracia 2000, Hillier and Barrow 1999, and Fox 1996), it behooves researchers to study how illness is perceived, experienced, and endured by Latinos. Their experiences are unique and exaggerated, which makes it an important subject to research. This study seeks to make a contribution to the literature on health and illness that will help to fill this gap in our current understanding of illness, culture, and gender.

Chronic/Life Threatening Illness: An identity entered into by those with chronic and life-threatening illness has been studied extensively and is often referred to as the sick role. An ill person tends to feel as if they have suffered a loss, as if a part of them has changed because they are ill (Charmaz 1991, 1995, and Baker 2002). They do not feel as if they are the same person now that they are sick (Nochi 2000, Rier 2000, and Waskul and van der Riet 2002). They often feel dependent on others, and must passively acquiesce to an uncontrollable illness. When a person is diagnosed with a chronic/life threatening illness, they experience more than psychological changes. Their body feels

² “The largest segment of the U.S. population (approximately 45 percent) is the *working class*, comprised of such people as factory workers, construction workers, furniture movers, and appliance repair persons” (Ferraro, Trevathan, and Levy 1994:429)

differently and such changes work to reinforce an identity as a sick person (Corbin 2003).

Juliet M. Corbin (2003) writes:

The body is more than just an object to be decorated and enhanced. It is more than a physiologic organism functioning according to a prescribed genetic code...

It is, as Merleau Ponty (1962) states, the embodiment of who we are (p. 258).

During illness the body can become "...unruly" (Waskul and van der Reit 2002:487).

People who are diagnosed with blood disorders such as leukemia often suffer from symptoms that include but are not limited to huge lumps on their chest, bruises all over their body, and perhaps blindness. Those who undergo radiation and a bone marrow transplant may experience burning of the esophagus, uncontrollable bowel movements, and the swelling of their face, hands, and feet to mention a few. These experiences are not unique to Leukemia patients. As Dennis D. Waskul and Pamela van der Reit (2002) tell us, "Cancer [breaks] through normative boundaries" (p.487). Such an experience makes a person feel as if they have lost their sense of personhood due to their illness. It is not normal for the body to react this way, and yet ill people are limited in their ability to prevent such changes from happening. Frank (1991) tells us: "When a person becomes a patient and learns to talk disease talk, [the] body is spoken of as a place that is elsewhere, a "site" where the disease is happening" (p. 12-13). By using such language, others reinforce this loss of self.

Although many ill people assume some variation of the sick role, such a transition is not uniformly experienced across class, gender, and racial groups (Rodriguez 1999).

Yet, there is very limited information in the literature from the perspective of non-professional non-white males. When a study on people with chronic/life threatening

illnesses is conducted, whether it is about how they cope with illness, or how their identity changes, the group studied tends to be Caucasian (Hutchinson et al. 2003). Even when studies are conducted on a specific type of illness, researchers tend to discuss how that specific illness affects Caucasian men or women, and in some cases both. In one particular study that compared men and women, Vivienne Walters and Nickie Charles (1997) found that women's coping mechanisms seem to work better than men's. This assessment prompts several questions. In what way do women cope differently than men? What role do relationships play in this effort to cope? Does women's general subordinate position in society make it "easier" for them to relinquish control to medical authorities? Similar questions can also be asked about the coping mechanisms of people of color. How does their social location in relation to the larger society affect their relationships with their family, the medical staff, and community organizations? When we look across race-class groups, we can add other dimensions to the experience of being ill by asking such questions as why does the literature only focus on coping? How come studying the sick role seems to get reduced to an analysis of coping behavior? When people have a chronic/life threatening illness they experience constant identity transitions. Every day, week, or month raises new symptoms, which might compromise an earlier vision of oneself. Thus, it is clear that we need to explore questions perhaps more fundamental than "coping mechanisms", such as the kinds of identity transitions people experience and how these transitions are experienced by groups not typically studied in the literature such as young Latino working class men (Petersen 1998, Wilson 2004, Groce 2005, and Santana-Martin and Santana 2005).

The concept of gender work provides a theoretical tool for analyzing the various identity transformations experienced during a long-term chronic/life illness. Although this concept has been typically applied to women and how they reenact a vision of femininity through daily work and interaction, it becomes useful for seeing how Latino men must renegotiate their masculinity which is one of the most fundamental parts of their sense of self.

West and Zimmerman (2002) emphasize that the “doing of gender” is an activity that is engaged in by both men and women. “Gender is not biological, it is a complex of socially guided perceptual, interactional, and micropolitical activities that people accomplish in their way of being” (West and Zimmerman 2002:4). We learn how to become men and women and how to enact roles that are consistent with larger cultural expectations of masculinity and femininity. Culture is reproduced, maintained, and at times challenged by the work of people. The reproduction of gender is not biological, it is social. By analyzing Latino males’ identity transformations, we learn about the kind of gender work these men do to renegotiate a sense of self, given their social predicament. Although in this case we are observing extreme social conditions (serious illness) for understanding gender identity transformations, such a process will help us understand how many men at various points in their lives renegotiate a sense of self that “works” for them as their circumstances in life change.

The Social Construction of Masculinity: It is uncertain how the term masculinity and its meaning emerged but it began some time around the turn of the nineteenth century. Masculinity was understood to mean “manhood”, which eventually [later] was understood as “adulthood” (Kimmel 2005). At the turn of the nineteenth century

masculinity was recognized as describing a man who “accepted responsibilities such as being a provider, producer, and a protector of family” (Kimmel 2005). During this time, two models of manhood prevailed (Kimmel 2005). The first model is called the “Genteel Patriarch”. This model “describes the manhood of the landed gentry” (Kimmel 2005:38). Men had a “redefined elegance, a casual sensuousness, and [were] devoted father[s] who spent [their] time on [their] estate with [their] family” (Kimmel 2005:38). The second model of masculinity was called the “Heroic Artisan” (Kimmel 2005). These men were urban craftsmen and shopkeepers “who embodied...physical strength”, also were devoted fathers, and “taught [their] sons [their] craft” (Kimmel 2005). A Heroic Artisan was also an “economic liberal who cherished his workplace autonomy” and who participated in democratic town meetings (Kimmel 2005:38). By the 1800s, masculinity began to change and a new version of masculinity began to emerge beginning in Europe then spreading to America (Kimmel 2005:38). This masculine identity is called “Marketplace Manhood”. It was described as the “new man” identity. Men began to focus on capitalistic views of wealth, power, and capital. He was “an urban entrepreneur, the businessman, was restless, agitated, devoted to his work in the homosocial public arena. He was thus an absentee landlord at home and an absent father to his children” (Kimmel 2005:38). The identity of the “new man” seems now to be subsumed under the concept of “the new hero”. The “new hero” is a male who is a tough intellectual and who has characteristics such as being rude, crude, and clumsy. He boasts political apathy and is independent and self-serving, showing no concern for anyone else (Segal 2000). Although the concept of masculinity initially had positive connotations, now it became associated within society with negative characteristics (Segal 2000).

This quick historical account of the term masculinity provides a context for how Latino men have borrowed from some aspects of a typically European notion of the term. While Latinos uphold an image of masculinity that demonstrates a strong sense of family and responsibility, Latinos in the U.S do not often have the same opportunities as other men to participate in politics or pass down a trade to their sons (Stier and Tienda 1993, Guttmann 1996). Yet, their identities are very entrenched in a version of masculinity that requires a capable and healthy body and mind. In the following chapter, I will discuss the concept of Latinismo to illuminate why it is critically important to these men to renegotiate a sense of masculinity to preserve self respect and pride when ill health compromises their abilities to maintain traditional images of masculinity.

Latino Masculinity - A Distinct Role: Although there is great differentiation in the Latino culture about gender socialization and expectations, there are several distinctions separating Latinos from the general population (Padilla 1985 and Johnson et al. 2002). Social class and geographic location, however, temper some of these differences. Francesco Cordasco and Eugene Bucchioni (1973) tell us about Latinos specifically:

The actual degree of control that a man exercises over his family varies a great deal, both from class to class and from region to region. The husband's authority seems to be strongest where the family is poor and where the husband controls all the resources. In these families the wife and children work under his direction and submit completely to his demands (p.62).

In a Latino family, the man generally is considered the head of household and women are expected to do all of the household chores, which include cooking, raising children, and being a “good” wife. Male and female children are raised differently as well. “From babyhood on, boys and girls are separate and each is taught to associate only with members of his own sex” (Cordasco and Bucchioni 1973:63, Kent 2000, Abalos 2002 and The 2004). Girls are often highly protected, while the boys are often taught to be workers and providers like their fathers. “Middle and upper class Latino men, in particular Puerto Ricans, exercise more authority in their homes than do American men” (Cordasco and Bucchioni 1973:62, Kent 2000, Abalos 2002, and The 2004). In general, “the less money a Latino family has, the more we note an authoritative male-headed household” (Cordasco and Bucchioni 1973:62, Kent 2000, Abalos 2002, and The 2004). Given the difficulty of making it on one salary (Hochschild 1989), many Latinas enter the workforce, which tends to boost the household income to working class. With women working, the women themselves claim more autonomy. Yet it is still important for Latinos to earn more than their wives. Cordasco and Bucchioni (1973:63) note:

In some of these cases the wife’s income may support the family or at least contribute a large share of it. The husband loses his authority to dictate his wife’s activities when she works outside the home and has a life and friends of her own. Internal strains in these families, given the ideal of strong male authority, are sometimes great.

Latino men take pride in their manhood. They pass that pride on from generation to generation (DeGenova and Ramos-Zayas 2003). As a result, they have trouble accepting their illness and the sick role. They do not tend to take their illness seriously, nor are they

comfortable admitting the seriousness of their illness. They do not want people to pity them.

Latinos, in general, do not want their family members to worry about their survival or their everyday necessities because that is a man's responsibility (Dicks 1996). When the "man of the house" does not meet those responsibilities, not only do others look at the man in a negative way, but also the man himself feels like a failure (Dicks 1996). As Alfredo Mirandé (1997) points out, "They have self-pride, they hold themselves as meaningful people. You can be macho as a farmworker or a judge. It's a real mixture of pride and humility. Individualism is a part of it—self-awareness, self-consciousness, responsibility" (p. 74). Latino men are not used to being dependent on others and are more comfortable with people depending on them (Vega 1995). They do not want to allow their family members to take care of them. They perceive such dependence as a sign of weakness. Mirandé (1997) supports such a belief by stating that a "positive macho theme was described as someone who meets [their] obligations, shoulders responsibility, [is] responsible for [their] family, fulfills the responsibility of his role...irrespective of the consequences, makes firm decisions...that take into consideration the well-being of others" (p.73). As a result, Latinos who become ill would rather maintain a traditional masculine identity and not share with anyone what or how they are feeling. Yet the kinds of chronic/life threatening illnesses that are being looked at shatter these men's ability to uphold a strict traditional image of masculinity. They quickly learn that the family as well as all of the extended kin rallies around them. The seriousness of their disease and the chronic illnesses associated with it requires them to rethink their image of masculinity. Consequently, we have much to learn about gender

work by listening to the stories of the Latino working class men I interviewed for this study.

Chapter Two

Methodology

As a Latina and daughter of a person who is battling a chronic/life threatening illness, I knew interviews would be the best method for this study. Meeting one on one with these men helped me see their struggles not only through their words but also through their actions. Such a sensitive topic can be well understood only by talking to the person and getting to know the person. It would allow them to see that I have a sincere interest in their struggles and what they share will contribute a great deal to our understanding of illness among Latinos. The recruitment procedure began by asking the participants of a cancer coping group if they would be interested in participating in a study about Latino men and their experiences with illness. After I gained the interest of the participants, I then called them about a month later to verify that they were still interested and able to participate in this study. All of the men eagerly offered to participate in my study. My father explained that he felt honored to be part of this study because he feels that it needs to be studied and understood in society.

I began my work by conducting in-depth interviews with four Latino men and their spouses in their place of residence. It gave them a chance to talk about their experiences in a comfortable space. Since they were in their own homes, I could see first hand how they negotiate their everyday lives given their illness. The subject matter I planned to study is often painful to discuss and requires Latino men to reveal very personal details about their lives. Often, even in health, Latinos do not feel comfortable revealing weaknesses and personal feelings to outsiders. Since these men knew my

father's experience they trusted my intentions with my research. They knew how important a study like this was to me as well as to the larger Latino community. As a result, they were open about their struggles with illness as well as with their lives as a whole. In-depth interviews enabled me to be sensitive to how these men experienced the ongoing changes that occurred in their lives as a result of being ill. I tried to maintain a role as a listener mainly asking questions as a starting point and using probes for further clarification (Strauss 1987, Berg 2004, and Jones 2004). Other methods of research would not have given me such in-depth details into the lives of these men (Handbook 2000 and Rubin 2005). For example, if I used survey research, I would have had to depend on the literature for developing a questionnaire. Yet, in that there is no literature on Latinos experience with illness, I would have to rely on the experience of Caucasian men, which would reinforce the very notion that I had come to reject with my study. Those who do not fit this status group do not necessarily share the Caucasian experience. Participants were asked to speak freely on three open ended questions that they were asked. I asked further questions based on the information that they shared with me. Probes were used as well when information given needed to be further specified (Handbook 2000 and Rubin 2005). Such a sensitive topic calls for this type of analysis because it enables the person to have as much control as possible over the content and flow of the interview. The data collection consisted of twelve open ended interviews³ over a three month period. Each interview took approximately 1-3 hours. Each participant⁴ was interviewed a total of three times. After each interview, I took more

³ See Appendix for a list of the Interview Questions.

⁴ All names in this study have been changed for the protection of the research participants.

extensive field notes. I used the information I had hand written in a three ring binder to help me write more detailed notes later.

For my initial interview, I decided to learn from the person whom I know best. This person is my father who is Puerto Rican and is battling Chronic Myeloid Leukemia and Hodgkin's lymphoma. His name is Nelson and he is 45 years old. He has been battling leukemia since he was 32 years old. At the age of 37, he was also diagnosed with Hodgkin's lymphoma. He grew up in the Bronx and has worked since he was about 15 years old. In his late teens, he worked in warehouses. He would pack up goods and load them on a truck so that they could be delivered. He engaged in this type of work in the Bronx and later in Florida until he became too ill to continue. He is married to my mother who is also Puerto Rican. They met in the Bronx and have three children who are now all adults (ages 26, 24, and 23). My father is now permanently disabled and continues to battle with his illnesses. In that I live with my parents, I thought it would be beneficial to keep a detailed log on my father. I was not able to do this with the other research participants because I do not live with them. By logging his behaviors, I was able to see how his life changed daily. This log documented his demeanor, behaviors, and illnesses as well as the overall struggles of living with a chronic/life threatening illness. I documented such events as the circumstances under which my father sought out medical assistance. I also noted changes in his relationship with family and friends, which was often linked to how well he was feeling on a particular day. I took notes on his stamina each day and the level of tasks he was able to accomplish. This log is an invaluable tool in exploring how my father redefines even the simplest accomplishments like walking to the mailbox as an achievement. Without being able to work, the

accomplishments of all sorts of household tasks enable him to have a sense of mastery. After keeping a log for about two and half months, I proceeded to interview three Latino men who I will introduce below.

Michael is 40 years old and been battling chronic lymphocytic Leukemia (CLL) since he was 34 years old. He was born in the Dominican Republic, but was raised in Brooklyn, New York. He is a painter and has maintained this career for a very long time. He and his wife met in the Dominican Republic and later moved to Brooklyn. They have two children, one is a 12-year-old boy and the other is a 9-year-old boy. Although in remission, Michael continues to struggle with CLL. He still works because he is unable to get Social Security Disability Insurance⁵, which is something that people have to qualify for. Michael was not approved for SSDI when he initially applied and because of this he is forced to work. Since the cancer was in remission, social security denied him and felt that he could work. He explained that he had his doctors supporting him but the people who decide on who qualifies for SSDI felt it was probably less a matter of feeling and more a matter of the inability to fit Michael's disability into their bureaucratic categories. To Social Security, Michael was healthy enough to work. Bureaucracy does not see what he goes through on a daily basis because of his illness nor do they care. With such a serious illness, just because the Cancer is not active, does not mean that they are healthy again. At times, from what I could remember with my father, the treatments were harder on him than the actual illness.

Juan who is Puerto Rican is battling Hodgkin's lymphoma. He is 42 years old and was diagnosed with Hodgkin's lymphoma when he was 35 years old. He and his

⁵Social Security can be short or long term. My father was first on SSDI for a short period of time (3 years), then when his time ended he came up for a review and since his health had declined so much, with the help of his doctors, he was considered permanently disabled.

wife were both born in Puerto Rico where they grew up and got married, but afterwards moved to Chicago, Illinois. Juan is a car mechanic and has been employed in this field for a long time. He enjoys working on cars very much and has his certification. He has three children: two girls who are 11 years old (twins) and a boy who is 9 years old.

Alex who is Cuban is battling a blood disease called Aplastic Anemia. He is 35 years old and was diagnosed with this disease at the age of 31. He was born in Philadelphia, Pennsylvania, but grew up in Florida. His wife is also Cuban and she grew up in Miami. He has been a carpenter for a few years. He has two children, one girl is 10 years old and her sister is 8 years old. Alex was working for a short period of time, but now receives disability benefits because the illness as well as the treatments debilitated him.

In the next chapter, I will show how these men envisioned their masculinity, how they were raised, and how illness abruptly required an almost immediate externally forced transformation in their role as men (Denzin 1987, 1989) and their sense of manhood. It was in early childhood when these men learned who they should be as men. With the onset of illness, this image started to crumble, as they felt compelled to renegotiate their images of masculinity in order to preserve some sense of Latino masculinity.

Redefining Masculinity

Chapter Three

This isn't supposed to happen. I thought I was too young for cancer. How am I going to take care of my family? How am I going to be the man that I was being sick and depending on people? It's not fair to them or to me.

Alex (Research Participant)

When these men recalled growing up, all of them referred to the importance of upholding very traditional Latino expectations of who they should be as men. They learned early to control their emotions, be responsible, and work hard even if their own male models did not uphold such an image. These men did not grow up in privileged homes. They came from very poor backgrounds. They hoped for a more secure or better standard of living than the one in which they were raised. As illness sets in, the image that these men uphold of the cultural ideal begins to crumble. They know that as men, they are to take the lead in the household. They are supposed to be strong and not be emotional. They are supposed to be the rock of the immediate and extended family. They are not used to depending on family for help or relying on doctors for their survival. These men are supposed to be hard workers no matter what happens and are to assume responsibility for whatever is necessary. As illness settles in, these cultural ideas or learned behaviors get shattered. All of a sudden they are not able to take the lead in the household so their wives must assume financial responsibility. They begin to share their emotions because their future is uncertain. They are angry and scared. All these changes that occur as a result of their illnesses require a transformation in these men. They

expected life to have daily stressors and occasional problems, but they never imagined living their lives each day happy to just be alive.

These men planned on having normal lives but that drastically changed when they began to feel ill. They were in the prime of life, in their 30s. They each had a wife and young children and each held a decent paying working class job. At this age one does not expect to be ill. Even before the initial diagnosis, their way of being begins to change. Their stamina, strength, and performance begins to slow down. Not feeling well is confused with having a bad day at work or just being in a bad mood. When the symptoms became worse, these men were forced to see a doctor. By doing this, they admitted to themselves and others that they believed deep down inside that they were very ill. All their life accomplishments such as creating a family, having decent jobs, and being able to take care of the household came to a crashing halt when the men recognized that they were ill. All four men explained that they avoided their illness for as long as possible until it became obvious to them that they must see a doctor. Nelson states:

I wasn't the type to get sick a lot. It had been years that I wouldn't get a cold. But then I started having colds and fevers that were unbelievable. I would take Tylenol to break the fever and that worked for a little while. But then my feet began to swell. And then these huge lumps on my body began growing. I would have a hard time at work because I did not have the energy. I began vomiting a lot and had unbelievable headaches. I also began bleeding through my rectum. I was not the type that went to the doctor. I hated doctors and still do till this day. I finally went to see a doctor once I lost vision in my right eye.

Most people would see a doctor because of severe headaches or rectal bleeding, but notice the complications and severity of the illness necessary for Nelson to acquiesce and see a doctor. All the men I interviewed waited until their symptoms were extremely severe for them to seek outside help. This is not uncommon as Latinos are noted for their lack of willingness to use the health care system (Zambrana, Dorrington, and Hayes-Bautista 1995). One part of such unwillingness, perhaps, is denial that they need help from others, as well as the resistance to moving outside the comfort of their community by seeking assistance from a medical system that is very foreign to them.

Watching my father struggle to see the doctor was difficult because he was not the type to go to the doctor. Yet, we all knew that if he did not go see a doctor as well as follow the doctor's advice, he would not survive his illness. My father feared that his life would be in the hands of doctors. It was as if he became vulnerable. All of the men explained that they had no choice but to see a doctor because they began having unusual symptoms and felt very ill. Their acknowledgment of their illnesses was the beginning of a major transformation at least in how they saw themselves as men. Their lives depended on submitting to medical expertise, which required them to relinquish some level of control. Doctors represent a type of authority and one that working class Latinos often do not completely understand and trust. Nelson tells us:

The doctor himself called me, so I knew that something was wrong. He told me to come into the office to see him as soon as possible. I asked him when should I make an appointment to see him and he told me, 'no appointment is needed you need to come see me today. When you get here check in with the nurses and they will direct you to my office'.

Although their experiences were not exactly alike, they all went through similar changes in their vision of what it means to be a man. They all felt vulnerable. They felt vulnerable because they no longer had control over their bodies, they did not fully understand what was happening to them, and now they had to depend on others for help. Nelson states, “The doctor told me to bring my wife with me to the office because he had something to tell me and did not want me to go alone”. They came to realize that they must trust outsiders for their survival as well as rely on family for help. Nelson’s doctor asked him to bring his wife with him. That way, Nelson and his wife would get the news about his health at the same time. Nelson was not given the authority to choose who, when and how he would tell his family members about his illness. The doctor decided for him. He recognized that Nelson’s wife would need to be the pillar of strength for him and the family.

When the men first found out that they were ill, they really did not understand. Miguel states, “I remember the doctor using some big words that I did not understand. The only word I knew was cancer and with cancer I just assumed people died...” Nelson states, “I felt so angry when the doctor told me I had cancer. It almost felt as if it was his fault even though I knew it wasn’t. I felt like such an idiot, I felt helpless”. As uneducated men, it was not unusual for them to feel like an idiot. They had a very limited medical vocabulary and were not used to instructions by medical personnel. After the initial doctor consultation, these men experienced more tests. Then, they received an official diagnosis. With an official diagnosis come further changes with these men. These men now are considered patients and experience the stigma associated with this title. With an official diagnosis of a serious illness it is “normal” for anyone to

feel such emotions as fear, anger, denial, helplessness, and vulnerability. However, Latinos do not accept such emotions easily. It is hard for them to accept their illness and the reality that they need help. Instead of these men worrying about others, others are worried about them. Nelson states, "As a Latino, we are the ones who people depend on. I like for family to come to me when they need me. I never thought that I would depend on anyone, especially for survival, for my life. I was always independent and learned how to be independent at an early age". As patients, they experience further scrutiny, tests, and dehumanization. They have a serious illness that must be treated. It does not matter that they are young, working class Latino men. They need to do what they can to survive which includes submitting themselves to medical expertise and the care of their family members.

Family Expectations: These men needed to be taken care of by their wives, their mothers, sisters, and even cousins. Now that they are ill, they have to depend on family members to care for them. They are unable to work and are unable to fulfill their responsibilities as men. During my father's recuperation from his bone marrow transplant, which took a whole year, my mother, his parents, and his sister-in-law cared for him. Both my mother and father's sides of the family were very involved during his time of treatment. If they were unable to visit him in the hospital, they would definitely call to check on him. Alex also had a similar experience:

My wife and sister helped take care of me. There were times when they had to bathe me and clean up after me. It's humiliating and embarrassing. My family has even needed to pay some bills for me. I should be holding my own and taking

care of my responsibilities, not having my family do it for me, especially not my poor wife. She didn't deserve that.

Now that the men need help from family members it is hard for them to cope with such a change in their lives. As Alex tells us it is humiliating and embarrassing to not uphold their part of the household and family responsibilities. Coupled with this shame, is not being able to care for themselves. Family members are involved in helping them fulfill the most basic functions of daily living such as bathing and feeding them much like you would a baby. They needed someone else to keep track of their medications and give it to them. For example, my father was taking so much medication that my mother made a system for herself. She could not keep track nor pronounce the names of the medications, so she put a letter on them to ensure that my father was getting the appropriate medication at the exact time he needed to take it. The letters went through the alphabet three times. Then in a notebook she wrote out all the medications with the appropriate letter, the time of day he was supposed to take it, and the amount of times a day each specific medication was supposed to be taken. The morning looked something like this: 2A (He needed to take 2 pills of bottle A), 1B (1 pill of bottle B), 3C (3 pills of bottle C), 4W (four pills of bottle W), 1AA (Saline solution to clean his catheter), 1BBB (A liquid to help his body not reject the bone marrow), 2KK (2 pills of bottle KK), 4SS (4 pills of bottle SS), and 2T (2 pills of bottle T). My mother needed to keep track of his medications every single day. These men knew they were incapable of planning such a complicated regimen of drug therapy and had no choice but to rely on their family for their survival.

Coupled with needing care from others, their daily routines have changed. Although most people can plan a vacation or a date with their kids or spouse, for these men it is difficult to plan even the simplest of tasks. Their ability to do anything is connected to how they are functioning that particular day. Everything they do takes so much effort. Despite being taught from a young age to develop their strength and stamina, with such an illness these men do not know what to expect daily. They used to take pride in their bodies since many of these men work physically demanding jobs. They were used to putting up with simple aches and pains that come from a tough day at work, or playing sports. Yet now, these men are unreliable. They must monitor their stamina daily to determine the extent of their activities for the day. Miguel states:

It will be Monday and my wife will ask me if we as a family can go to the beach on Saturday. I tell her that I do not know I will let her know Saturday morning. I do not want to tell her yes and than Saturday comes and I do not feel good enough to go.

Miguel explains that some days he does not feel bad. Yet, other days he gets home from work, says hello to his wife and children, and then heads straight to bed without even eating dinner because he is too tired to function anymore. Monday through Friday his daily activity involves working. On the weekends he tries to be involved with his family, but his lack of energy sometimes interferes with being able to fully participate in their activities. He also misses work during the week, which affects his paycheck leaving the family finances extremely tight. Much of his paycheck is spent on co-payments to see his doctor and for medications that he needs every month.

Tight family finances are just another reminder to these men about how they are unable to fill their roles as providers of the household. Illness not only requires changes in these men, but also their relationships. Since receiving the official diagnosis, these men have experienced noted changes in their ability to hold up their part of the bargain in the household. They are unable to be independent. Others must care for them. They have difficulty making commitments to the family. Their ability to be involved in any family activity must take into account how they are feeling that particular day. They have difficulty being the main breadwinner, since they either cannot work or are unreliable at work.

Marital Expectations: At times, they have difficulty functioning in the one place where men are expected to show their masculine prowess. Juan states:

My wife and I do not go out very much. I feel guilty because at times I know she felt neglected and as her husband I felt as if I could not be there for her. We couldn't have sex when I first received my treatment. But when we did have sex I was barely able to continue. It was embarrassing and humiliating.

Alex states:

My wife wanted to have another baby once I was done with treatment. We had talked about it before I got sick. Once I became sick and had a bone marrow transplant, I became sterile, and was unable to give my wife another child. I know she was hurt about that even though she said it was ok that she was just happy to have me alive. I felt like a failure. I felt like damn I can never give my wife another child, how could this be?

Once again these men feel embarrassed and humiliated as a result of their illness. They feel like failures. They have trouble fulfilling their marital expectations as well as being unable to father more children, two very strong indicators of their masculinity. They begin to lack a purpose in life, which greatly affects their relationships with other people.

Work Expectations: Coupled with all the numerous changes that have take place within their household due to their illness, are the numerous compromises that occur at work. If they feel ill, they cannot function at their jobs. Some men are no longer able to work. Getting help from family and friends is hard for these men to accept, but it is even more catastrophic when outside agencies and welfare become the main way these men get the bills paid. Nelson states, “I went to get food stamps because I was not working at the time and social security hadn’t kicked in, and my wife’s income was not enough to pay all of the bills”. All four of these men grew up on welfare. Welfare at the time was governmental assistance. The government gave people cheese, milk, peanut butter, bread, and eggs. Families were given food stamps that were worth one dollar, five dollars, and ten dollars, just enough for families to have the necessities. Aside from having to pick up the welfare money, people would go to facilities to literally pick up the food mentioned above. The last thing they ever wanted was to depend on the government for their survival. Yet they had no choice but to turn to an agency for help because they could not survive financially. Nelson states:

I was trying to go to work and get myself active again. I remember one of my supervisors wanted to write me up because I missed too many days from work. I had to go to the head manager and talk with him so that any days I missed wouldn’t count against me. It worked for a little while, but then eventually I had

to quit...I remember going to work and leaving after pushing myself to work one hour. I just couldn't do it.

I remember when my father had to locate extra finances because they were going to foreclose on our home because we had not paid the mortgage in about two or three months. He also tried to work but could not. My father encountered many struggles as well when he was working. Often such struggles occur with other workers who do not understand what it is like to not have a fully functioning body. Interactions at work which question these men's use of sick days are a constant reminder to them that they are unable to fulfill the expectations of what it means to be a male head of household.

Nelson recalls:

I had one idiot at work come up to me and ask me 'Hey Nelson how do you get so much time off and not get written up'? I simply told him 'Just get cancer man that's how'. It was like a joke to him. He did not know what I was going through the days I had to stay home, he did not know what I had to go through the days I had to go see my hematologist oncologist, he didn't even know what I was going through at work.

Notice how it made Nelson feel. He was angry because people were not empathetic or supportive. They looked at his days off as if he was having a good time, but what he was going through was far from fun. The men who still try to work find it hard to be very dependable. Juan's employer was pretty supportive when he was first diagnosed. He took a leave of absence for a year and a half to recuperate. He is a mechanic and has been doing this kind of work for many years. Yet, even for the most supportive companies, dealing with an unreliable worker gets old. When his sick days run out, they

do not seem to be as understanding anymore. These men all explained that as the years pass people are not as supportive and understanding as they were with the initial diagnosis. Juan states:

My co-workers were very supportive in the beginning, but it seems as if they really just do not understand. They think because I come to work that now everything is fine. They do not realize what I go through on a daily basis due to the cancer. When I am out of work and I explain that I was not feeling good, they look as if they do not believe me. And when my sick days run out the rest of the time I take off is without pay.

It is hard to protect oneself from the damage of such a blow to the basic core of their sense of self. These men can no longer provide for their families. Everything in their lives is greatly affected.

Sense of Self: I can remember when I was younger; my father was a different kind of person. He was energetic and high-spirited. He would constantly take my siblings and me out to different places and do things like swimming at the beach or going to the park to fly kites. Even when my siblings and I were kids these activities stopped because my father became ill. Changes came drastically and have lasted for a long time. This is not something that comes and goes. It lingers and changes, but does not go away. The house revolves around the men because the changes they are going through affect all aspects of their lives. The things they were able to do before are now a burden physically, but their minds still want to do things they did before. A good example of this is being able to work or even spending time with the family. It all changes because of illness and with that comes the redefinition of their masculinity.

The recognition that these men are ill creates a whole avalanche of changes: changes within themselves, changes with their family, changes with work and coworkers, changes in their community of care, as well as an emergence of the use of members outside the circle of friends.

In the next chapter I will highlight the spaces these men carve for recreating a sense of manhood. They redefine even the smallest tasks, ones typically defined as female oriented as a sense of masculine pride and accomplishment. While under the care of doctors and hospital staff, men find spaces for setting limits on the care that these officials provide for them. All of these struggles for control occur under the larger umbrella of being ill. Their illness will never go away. It is a constant and never ending process for them. Since this battle can never be won, they must redefine their ultimate goal. They win the battle, by being able to battle. Being able to battle preserves a sense of dignity. They try to have a sense of dignity despite living with a very undignifying disease.

Gender Work After Diagnosis

Chapter Four

Although these men's illnesses have meant major compromises in their traditional vision of masculinity, the men with whom I spoke demonstrated the creative and social processes involved in doing gender. What it means to be a man or a woman is socially created and has the potential for change. These men engage in identity work that enables their behaviors and actions to get defined by them in such a way that it supports the larger cultural ideal of Latino masculinity.

In this section, I explore the tension around the kind of work involved in upholding a renewed image of masculinity within the larger parameters of being ill. Men do carve out spaces of masculinity, but such an image is different than the one under which they were raised. There are few spaces for assertion and yet when available, men may choose to assert particular desires—like no guests, no worrying about me, a desire for a particular hospital room, or deciding when to see the doctor. Yet, unfortunately their illness rules, and it is completely unpredictable. So, how do men do the work of repairing their masculinity under an illness that has no boundaries? It is a constant negotiation with very small triumphs. As a result of their chronic/life threatening illness, a particular kind of home is established. The man is head of the household. Yet, no matter how hard it is for family and friends, it is still the hardest for these Latino men. The whole house centers on them—their moods, their daily needs, what they can and cannot do. After a short period of time, their illness has transformed the house. And yet, there is dissatisfaction in this arrangement as head of household. It is based on infirmity

and sickness. As the men continue in their transformations, the one place that is supposed to be peaceful and calm is full of tension: the home. The moods of the men are hard to deal with. The rest of the household wants to be there for them, but it is exhausting to deal with them. The household never knows what mood to expect each day. And of course the mood depends on how the men are feeling for that day or at a particular time.

The home drastically changes, but in some ways it stays the same. There is the constant worry and the threat for him to become ill. At home not only are these men dealing with a serious illness, their relationships with spouses, family, and friends are all affected. With the onset of illness comes a change in relationships with different people. The men are unable to care for others, and also people who were once sympathetic toward the sick person lose sympathy after time passes. Relationships with spouses change over time due to illness. The changes in relationships are hard on the men as well as the other people. People often do not know how to act or react to them. Changes affect all of the people that are involved in the lives of these Latino men. Below I share a section of the log that I kept on my father. I kept a log for about two and a half months. When documenting his behaviors, I would think about how things used to be in our household and how it had changed so much. The one thing that stays the same is that my father is sick. He spends weeks in bed. Here is a look at six days in my home.

Monday December 13, 2004

- My father got up early to check the mail, which is his daily routine. He told me that he felt tired because he does not sleep very well at night. He says that

he has dreams of death at night. My father wanders during the day trying to look busy.

Notice here how my father tries to look and feel busy. He seems to want to be productive. Looking busy shows us that he is productive and that he is not dwelling on what is wrong with him and his illnesses.

- My mother and father got into an argument when she got home from work. My mother wanted to go out to eat. My father said he didn't feel like it. He wanted her to cook and she refused.

My mother tries to do different things with my father, but he never feels up to it. My mother hates arguing with my father because of how it makes her feel. She needs to stand up for herself, but at the same time she feels bad that she is arguing with her sick husband. She says that she hates arguing with him because what if she says something that she regrets and then something happens to him? My mother is hurting because she has been struggling with my father's illness for years, but at the same time she is happy to have her husband alive.

- He spent most of the day in bed. He got up to see what was for dinner. After my mother and father got into the argument he went to sleep until the next day.

Notice that fights occur under different parameters. It is hard for my mother to assert her desires. Fights are different now. They seem to take on a new meaning when a partner is ill. It is hard for my mother not to give in to my father's desires. Instead of communicating about their problems, my mother says nothing and gives in while my father withdraws. He knows he is being demanding and that his wife is extremely exhausted. At the same time it is hard for him to feel sympathetic since he often does not

feel well. Although it is an expected part of Latino culture for men to demand labor from their wives, here the roles begin to change. My mother can no longer do extra work for him at home because she is working so much more in the labor market than either of them would like. Because he is ill, his demands are excessive. My mother now has more responsibilities in the house. She is responsible for her role as a wife and mother. She is also head of household because she brings home a paycheck and works full-time. Expectations are renegotiated because my father's position has changed. He is no longer the main breadwinner in of the household and while my mother is at work, my father is the one who is at home, cleaning the bathroom, running errands, and doing the grocery shopping. Although as a Latina, my mother is expected to meet my father's demands, it becomes too much at times. She must protect herself. She carries a lot of the burden and my father knows it and so therefore he must give in.

Tuesday December 14, 2004

- My father woke up and was vomiting a lot. He was very sick. My mother had to stay home with him because he would not stop vomiting. He would stop breathing while he was vomiting. He did not want to go to the hospital. My mother called his Hematologist Oncologist in Gainesville Florida and Dr. Jacobs called in a prescription for my father.

Notice here how my mother has to go against my father's wishes in order for him to get some help. Expectations of what men need from women have always been there, however under illness it is a lot higher. Men, to some extent, expect women to raise children and take care of the home, but notice here that my mother has to look after my father as if he were a child. My father never expected my mother to call his doctor

because she's always respected his wishes, however my mother felt that she had no choice.

- I went to the Walgreen's where we pick up his prescriptions. My mother gave him the medication and he slept for the rest of the day.
- We woke him up in the evening because my mother had made him chicken soup. He ate a little bit, then went back to sleep. He said he had no energy to sit up.

Wednesday December 15, 2004

- My mother and sister had to go to work. I stayed home to take care of my dad. He got up one time to take his medications, then he went back to sleep. I did not disturb him all day. I kept checking on him to make sure he was still breathing.
- My mother and sister called every chance they could to check up on him. We are very worried.

Thursday December 16, 2004

- My father is battling shingles along with all his other illnesses.
- Once again he spent the day sleeping. He was in a lot of pain and was having a hard time breathing.
- I was home with him again. He told me that that he is tired of being sick and being in pain. He wants it all to go away.
- I tried rubbing his head and he told me not to baby him. So I watched him fall asleep and left him alone.
- When my mother got home she tried to give him a hug and he pushed her away.

Here you can see how he redefines affection. He sees it as being babied and as a sign of weakness.

- He ate a light dinner, took his medications, and then went to bed.

Friday December 17, 2004

- My father woke up feeling a little better today. He checked the mail then came inside and asked me if I was doing anything today. I told him no. He asked me if I wanted to go out to lunch and I agreed to go.

Being able to go out to lunch can be seen as an accomplishment. He is healthy enough to get out of the house, and uses the family finances to do so. It is a little piece of luxury despite all the hardships.

- We went to Tony Roma's for lunch. We had a nice conversation. I asked him how was he feeling and he said better than the last 2 or 3 days.

Although my father deals with friction and his illness by withdrawing, he is still able to engage in meaningful conversations. Yet, he controls when he is ready to converse and what he is willing to say. When questioned by us about what he is feeling or thinking, he just brushes it off. Sometimes, on his own terms, he is able to open up, but my mother and I have to practically interrogate him to get him to talk.

- We had a serious talk. He told me that no matter what happens to him, I need to continue my studies and my life. We need to be strong. Then he said, "I'm not going anywhere. I'm not dying until I'm in my 90s". After that we went straight home because he was already getting tired. He listened to music until my mother got home.

Saturday December 18, 2004

- This morning my father woke up to check the mailbox.
- My father wants to be secluded. He doesn't want any visitors and he does not want people calling. He says when people visit and call too much it creates drama that he is tired of. He gets upset when anyone comes over. He wants to be left alone although my mother, sister, and I enjoy family visits. He has been non-communicative. When asked how he feels, he says he is fine.

Again his wishes come first. We feel an obligation to do as he wishes because we do not want to upset or hurt him. We do not want him to get sick again. The thought of losing him is always at the forefront of our minds. We would never want our last days together to be filled with tension, resentment, and frustration. So whatever happens in the household, we try to ignore it as much as we can. It is hard to minimize such negative emotions because my father as well as the rest of the household has been struggling with his illness for so long

- He has been fighting a bad cold. He knows that it can easily turn into pneumonia if he does not get treatment. He refuses to go to the doctor.
- I feel like my father is miserable and he is making the rest of us miserable. I do not know what to do. I do not understand.

These are some of thoughts that develop in my mind when life at home becomes unbearable. But the most important thing is that we do the best we can because I would rather have my father with us than not.

In this log, several themes are noteworthy. First, although traditional Latino masculinity defines accomplishment as hard work in a labor force job, men who are

forced to play the sick role redefine what counts as an accomplishment so as to retain some sense of their own masculine self-worth. Even the simplest tasks are often burdensome to these men. On a good day, my father can converse, walk to the mailbox, go out for lunch, drive a car to visit his mother, and pace the house looking busy. It is hard to take pride in any of these activities. And yet, these men find a renewed way to think about even the simplest task. Getting out of bed is an accomplishment and is the prelude to a productive day. Second, a husband or father's illnesses imprisons the entire family not just the person who is ill. Their needs are endless. While Latinas are traditionally expected to be caring and taking care of the household, now such care is enormous. Day by day it is difficult for women to assert their needs. When either side tries to assert themselves they begin to feel guilty. The ill person has the right to be the center of the household. His needs must come first. And yet, his needs are so demanding. These men know their needs are demanding too, which often makes them feel worse about disagreements. The wives know that the needs of their husbands are demanding making disagreements difficult for them as well. Third, there is no way to beat this illness. Given the kind of illness these men have, they will get other illnesses, which require constant supervision, vigilance, and worry. When my father has one good day we have to enjoy it because it can be a long time before he has another one.

Control: The daily log shows how little space there is for these men to live with a sense of dignity. They never know what each day will bring. Despite this situation, they put the little bit of energy they have into trying to normalize their lives. One way they try to do this is by attempting to control changes in their lives by resuming old routines as much as possible.

For some men Church was a big part of their lives before they became ill so being able to go again shows these men that they can have pieces of their old life back. Juan states:

Church for us is important. I remember when I got sick I was unable to attend many sessions. But when I was healthy we were regular at our church. Now that I am able to, I attend church when I am feeling better. I feel like I was never gone when I'm there. It was part of my life before I got sick and now that I'm sick I feel that it is even more important now to stay close to God.

Keeping the tradition of going to church helps these men feel as if their lives have not changed too much. This gives a different kind of strength to the men. It is far beyond physical strength. It is a spiritual strength, which no doctor, hospital, or family member can provide for them. Alex states, "I am Pentecostal and I feel that my faith in God has helped. Religion plays a big part in my family's life. I feel like my faith in God has kept me alive". Religion is an important part of these men's lives because it helps them feel normal as well as allows them to spend time with their families. When these men go to church, they go with their family. That's how it was before they became ill so they try to maintain this routine during illness. Going to church gives some kind of meaning in their lives since it was part of their lives before they became ill.

Appropriating Feminine Tasks: Spending quality time alone is no longer a luxury. They want to spend as much time with their family as possible. Nelson states, "There is no time to spend alone. I live for my family, for you guys. If it wasn't for my wife and three kids I most likely wouldn't be alive and who knows if I was alive if I would want to be". Miguel states, "I love spending time with my family..." Now that

these men are ill, they are more expressive. They are more emotional and they do not want to be alone. Spending time with family is of utmost importance to them. Each day when they feel well enough to get out of bed, they try to invest a lifetime's worth of attention into their family. They push their children to pursue goals and have accomplishments. They want to witness their children's successes and accomplishments. For example, my father is so persistent about hurrying me along toward my educational goals because he says, "I know you're going to make something of yourself and I want to see that happen before my time is up". Although it is nice to have my father involved in my career goals, it creates more pressure on him as well as on me. Everything is so important. Everything takes on such great meaning for him. His sense of achievement is now channeled through his children's successes. Prior to being ill, these men had an independent sense of achievement; now being a part of other's lives and helping them pursue their goals is a way to create meaning for them. These men want to be close to their family. They want to be connected because no one knows when that will be taken away from them.

These men become committed to what is typically noted as women's work. They maintain relationships in the family. Traditionally women have been supportive of the children, and raising them in the home. They have also been the ones to take care of the house. They are traditionally the ones who clean the house, the ones who cook the meals, and the ones who do the family laundry (West and Zimmerman 2002). These are generally considered "women's work" (West and Zimmerman 2002). Although these tasks are typically recognized as "women's work" (West and Zimmerman 2002) these men appropriate it into their own accomplishments.

These men try to do different tasks around the house to help them stay busy. Nelson states, "I look forward to cleaning the pool. I have days when I push myself to do things around the house. And although I may pay the price because my body is unable to handle it, I know and feel in my mind that I have accomplished something. I'm even in charge of cleaning my bathroom". Some of the men explained that they do more around the house than they did before. Juan explains:

Before I was sick I would do the basic things around the house like fixing something if it was broken, do the grass, clean the cars, etc. Now these things seem so difficult for me but I push myself to do it. I really want to feel as if I am still capable. Now I try to do more. I like cooking, I'll mop the house, and I'll paint if it's needed, and I am even in charge of cleaning our bedroom every other week.

The productivity of the men suddenly changes. Most are unable to earn a paycheck outside of the home, but when their illness permits, they are productive in the house. Their work around the house is redefined by themselves as well as by people in the household as an accomplishment. Doing the chores around the house helps these men have a sense of purpose. It also represents something they can do. They are no longer able to fix cars or work on the roof, for example, which are all typically masculine tasks. Men judge themselves according to these masculine expectations. Men perceive that people will stigmatize them for not supporting their families the way a man should. Although housework may be considered "economically unproductive," (Folbre 1994) it is the best that these men can do because they are ill. Housework makes them feel

productive and like they are contributing something to the household. It helps the household as well as the men. Nelson explains:

Days that I'm feeling good, I like to get up and do things around the house. The days I'm not feeling well, I end up staying in bed all day and feel as if I'm existing and not living, as if life is dragging me along. Everyday I struggle, but some days are better than others.

Alex tells us:

My wife was the one who would cook and clean the house, but now that she works I felt that I should take care of the house because I'm not working. I didn't even know how to work the washing machine; I just knew how to fix it. My wife taught me and now I do the laundry in house. When a piece of clothing is missing, I'm the person everyone comes to see. When I'm able to do all the loads I feel as if I've contributed to my household. There are times when my wife has to take over the laundry because I just don't have the stamina to finish.

And Michael:

I never imagined doing things around the house such as sweeping and mopping. My wife was the one who took care of that. Now those are the tasks that I'm barely able to do. I work during the week and so on the weekends I will help my wife around the house. Now I have to hire people or call family to help with major things that I was able to do before such as painting the house, which is what I did for a living, taking care of the lawn, or repairing the cars.

These men take pride in cleaning the pool or being "in charge" of cleaning the bathroom and doing the laundry. They have a new outlook on their activities. Notice that being "in

charge” makes the task seem important. These men claim that, like a supervisor they are “in charge of cleaning”. A mundane, stereotypically feminine task now has new importance because these men define it as an accomplishment and as important. They have taken a couple of the most demeaning stereotypically female tasks and redefined them in a way to make these tasks and their positions seem important. This redefinition takes place gradually. Although these changes are drastic, they develop slowly. My father, for example, did not begin cleaning the bathroom as soon as he became ill. As time passed he found ways to make himself feel productive and useful. Housework has enabled him to regain a sense of dignity.

These men’s lives have changed. As a way to rebuild a sense of masculinity they redefine tasks and try to take some control despite having a very uncontrollable disease. My father for example, receives SSDI. His check does not get spent on frivolous items. His check goes toward the mortgage, the most important item—the roof over our heads. We all help pay the bills, which is hard for my father to accept because he is unable to work. My father must rely on women for being the breadwinners of the family. He cannot fight this reality but can take control over the finances by insisting that my mother’s check be direct deposited so that it is cashed and so that he has access to it. He mails out the mortgage payment. Once he is given the money, he personally goes and pays the other bills. He assumes ownership and responsibility with the family finances.

Reasserting Control: Latino men also gain control and make choices whenever possible even when it is detrimental to their health or relationships. Sometimes such assertions are detrimental to their health, for example when they refuse to call their doctors and seek assistance from family members. It is also hard on those who care for

them given their refusal to elicit help from others. They still ignore their illnesses and refuse to see a doctor until it is absolutely necessary. This is the way they feel they can manage their illness. Their illness is seen as something personal and intimate. They maintain rights over their own body by refusing to call a doctor.

When asked about his relationship with his doctor Nelson states, “I feel that Dr. Jacobs... gives me a hug every time he sees me. I’m not sure if it’s because he really does like me or because he hasn’t seen me in a long time. He knows I’m difficult, he understands me”. Notice how Nelson above is unsure about the doctor hugging him. He is not sure if the hug is because the doctor hasn’t seen him in a long time or is it because the doctor truly cares for him. Dr. Jacob’s genuinely cares for my father because he has been treating him for a long time; however, my father has missed some appointments with Dr. Jacob’s and goes a long time without seeing him just because he does not feel like going. His excuse is that he hates hospitals. Nelson states:

I hate going to the hospital, I only go if I really have to. When I was admitted to the hospital for my transplant, the nursing staff told me I would have to use a portable toilet because having a bathroom was too dangerous for someone to have after a bone marrow transplant. I caught a fit. I told them that if they did not give me a room with a bathroom, I would leave. I refused to not have a bathroom. I raised serious hell and I finally got what I wanted. How could I use a portable bathroom, which just did not work for me?

Notice that in a place that one would not think that a patient could have any control, Nelson finds spaces to assert his desires. These are places where these men have some control. Control is a part of regaining a degree of masculinity.

Latino men usually deal with the finances, household discipline, and family relations. However once these men became ill, this all changed. They were not able to uphold their responsibilities. All of a sudden their roles became burdensome, they were not able to do it, leaving their wives and other family members responsible. Alex tells us:

I remember seeing my wife so stressed. She had children to deal with and a sick husband. She had a breakdown and her sister had to come stay with us for two months to help her out. I was in the hospital and she was the only one in the house left to take care of everything. She was both the mother and father to the children when I wasn't there. When I had my bone marrow transplant I was too sick to even talk. I never imagined how out of control things got for my family.

Nelson tells us:

I always remembered having control in my household. I always worked, paid the bills and kept order in the household. My wife worked as well, but I made the most money and handled everything until I became sick. Being sick made me very passive. I felt that my household sprung out of control. My children were rebelling. My wife was distant. My finances were out of control, and my quality of life was at its lowest. I realized then, that I had to do something. I needed to make my life productive again and make it have some kind of meaning. Because my family saw me breaking down, its like they broke down as well.

These men had to find ways to regain control of their lives and they did this by doing what they were able to do, to the best of their ability and taking pride in doing so.

The life these men lead, like that of so many other ill people, is exhausting. It is exhausting not only for them, but also for their circle of caregivers. Their illness has

irrevocably changed their life as well as others. These men live every day with this knowledge. The household has changed around them; it revolves around meeting their needs. And as a result, these Latino men feel like half of a man. These Latino men have repaired their dignity by creating a new vision of masculinity, which blends traditional feminine attributes and tasks, as well as asserting a sense of control in the few places where they can.

The men with whom I spoke demonstrate the creative potential of people. Although they are extremely debilitated and expect to move from illness to illness, they find a way to regain a sense of purpose by taking pride in their limited and often stereotypically feminine activities that they can do each day. As a result, they have found a way to have a sense of meaning in life despite their serious illness.

Chapter Five

Conclusion

The purpose of this study is to share with the larger society and especially the health care community the important story of how Latino men cope with illness and how they reconstruct masculinity in the face of their illness. We learn that Latinos are so entrenched in a traditional vision of masculinity that being ill shatters their vision of what it means to be a man. Being ill for these men becomes another layer of marginalization. They are already marginalized because of the color of their skin, their financial status, their language barriers, their educational status and their distrust of members outside of their Latino/a community. Now these men experience another layer of marginalization, which is a serious and life threatening illness. As a result of their illness, they are forced to seek help from doctors, the government, and social service agencies. The doctors are almost always Caucasian or some other racial/ethnic group that is not Latino. When these men have to seek financial help from social service and government agencies it is a painful reminder of their lack of financial independence. At the same time that these men feel marginalized outside their ethnic communities, they also feel alienated from their own immediate and extended families. Their families are essential for helping them cope with and endure their illness, but these men feel alone in their illness. No one can really understand how they are feeling or what they are thinking because in order to understand what they are going through, one has to experience it. But, by listening to the voices of these men, we can learn from their perspective about how they creatively try to piece together a life within the constraints of their illness

One of the biggest parts of their life that they must piece together is their masculinity. By studying how these men renegotiate what it means to be a man, we add to our understanding of gender work. These Latino men and their experience with illness represent an extreme case of remaking gender. Everyone makes and remakes gender. Many might question why it is important to care about gender work and the answer is because it gives meaning to a person's life. Most people throughout life find themselves confronted with the need to remake their gender identity. For example, when a woman becomes a mother, or people get married, or transition to a career, they are all remaking gender to fit their unique circumstances. Yet, these Latino men are in some ways different than the people mentioned above because they have undergone a radical transformation of self. This transformation is untimely and represents a battle that cannot be won. The way they are able to cope with the battle is to continue to battle.

Being ill has required these men to look at their lives and their capabilities from a new perspective. From the perspective of an ill person, these men think differently about the activities that they can do on a daily basis. Engagement in activities, regardless of whether or not they are traditional feminine activities, is a sign to these men that they have a purpose and can function to maintain the household. As these men who have been very entrenched in traditional expectations of masculinity creatively remake gender we learn about the fluidity of gender roles. The experiences of these men demonstrate that masculinity and femininity are not binary opposites. What is masculine and what is feminine become intertwined in ways that enable these men to live a more normal and dignified life.

Although my sample for this research is relatively small, this study provides a strong foundation for further research to be conducted on a much larger scale. Large-scale studies could determine, for instance, whether there are techniques for redefining masculinity that were not explored and revealed by the men in my sample. Another important subject for further research is to explore the role of the immediate and extended family and how family members must also remake gender. In particular, we can learn about how women transition their own thinking about gender to include being the head of household. Getting the women's point of view, will add to the complexity of our understanding of illness as well as situate it within a Latino/a framework that highlights the extensive care giving role of the immediate and extended family.

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Appendices

Appendix A: Open Ended Interview Questions

1. I will begin by asking the participants to tell me about their day. How would you describe your day from the time you get up in the morning to when you go to bed at night? (Probe: In what way do your daily activities vary from day to day? How come they might vary?)
2. Can you describe for me how it happened that you first noticed that you were ill? (Probe: What happened then?)
3. In what way is life different now then when you were first diagnosed? (Probe: Has it changed your roles within your household? In what way? How has your relationship with your spouse, children etc changed since being ill?)