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# Her-Storicizing Baldness: Situating Women's Experiences with Baldness from Skin and Hair Disorders

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Her-Storicizing Baldness:  
Situating Women's Experiences with Baldness from Skin and Hair Disorders

by

Kasie R. Holmes

A thesis submitted in partial fulfillment  
of the requirements for the degree of  
Master of Arts  
Department of Women's and Gender Studies  
College of Arts and Sciences  
University of South Florida

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## **Dedication**

I dedicate my thesis to my participants because without them this would not be possible. You all were more than patient with me throughout the research and writing process, and I am thankful for the friendships we created throughout this process. I also dedicate my thesis to my niece, Kailey. While writing my thesis, she told me she wanted to grow her hair out to donate to young girls like me. At the age of four, you are so smart and caring. I could not have done it without you!

I want to offer special thanks my parents, Stacy and Larry, and my sisters, Kylie and Kensie, who have experienced my condition and baldness with me. Although my dreams are ever-evolving, you all continue to support me without hesitation.

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## **Abstract**

A general goal to my study was to promote an inclusive approach to baldness by sharing and centering women's experiences with baldness from skin and hair conditions, such as autoimmune alopecia areata conditions and monilethrix. Specifically, a main goal of my study was to her-storice the lived experiences of women who are bald from skin and hair conditions by examining medical and cultural discourses surrounding these conditions, femininity, and female baldness. Additionally, my study considers strategies of accommodation and resistance that bald women perform in a given context, space, or time. For instance, I consider the ways participants manage their conditions and baldness within certain contexts.

To achieve these goals, I interviewed four women who are bald from alopecia areata, alopecia totalis, alopecia universalis, and monilethrix by using an interactive approach to the interviews. Once the interviews were completed, I used interpretative phenomenological analysis to extract themes across the four interviews. Based on the analysis, I organized the findings into two overarching themes that include (a) navigating the feminine ideal and (b) negotiating the assumptions of illness and female baldness. In these themes, I discuss how participants' experiences demonstrate the significance of accommodating and/or resisting hegemonic notions of femininity and illness.

## Chapter One: Introduction

Hegemonic, Western discourses on female beauty define attractiveness using a white, Western, middle-class, heterosexual, able-bodied representation of femininity. As Simone de Beauvoir (1974) states, “one is not born, but rather becomes, a woman” (p. 267). This means that particular disciplinary practices constitute the ideal feminine body, and women must follow these practices in order to be considered woman. However, the ideal female body is just that—an ideal (Bartky, 1990). Female bodies are accountable for performing the feminine ideal regardless of one’s purposeful submission to this discourse (Bartky, 1990). Bartky (1990) reminds us that the “disciplinary project of femininity is a set-up” (p. 72) because the expectations of the feminine ideal are drastic, extensive, and time-consuming procedures of bodily transformation, and any woman who submits to this standard is bound to fail to some degree. One procedure of bodily transformation that this discourse includes creates a specific, ornamented surface of the body. Specifically, the ornamented practices require that a woman’s hair meets certain requirements and maintenance (Bartky, 1990; Weitz, 2001; 2004).

Throughout history, expectations of femininity and styles change, but the ideals still center on Western, white standards and practices of beauty. For example, in the United States during the late twentieth century, dominant beauty norms around hair changed and privileged a “woman” who has long, straight or styled, blonde voluptuous hair (Synnott, 1987; Weitz, 2004). This historical shift in women’s hair is known as the “blonde revolution” and is still pervasive today (Weitz, 2004). Considering the

multiplicity of varying styles, lengths, textures, and colors of hair across women and cultures, this trend and discourse is limiting and exclusive. For instance, Black women's hair is usually visually "thicker, curlier, and often frizzier" (Thompson, 2008, p. 78). Accordingly, the texture and sensitivity to manipulation results in a different set of disciplinary practices and styling techniques for Black women and their hair (Bordo, 2008; Thompson, 2008). Therefore, there are time constraints and practical limitations to manipulating Black women's hair to the standards of the ideal femininity that assumes whiteness. Additionally, the rhetoric of "straight" and "natural" hair has particular, historical implications and cultural meanings for Black women in the United States, which has led to some hair being a site of politics and resistance throughout African American communities (Bordo, 2008; Thompson, 2008). Inclusion of hair outside of the dominant discourse of femininity, such as Black women's hair and baldness, elucidate that there are alternative ways of performing femininity. Performances of femininity outside of hegemony are significant because they disrupt the perceived naturalness of a true gender identity (Butler, 1990).

Although preferred lengths, styles, and colors of hair vary given historical context, the underlying assumption to be "woman" one must have hair remains unchallenged in dominant discourses. However, it is an overgeneralization to assume all bodies and specifically all women "have" hair or have the ability to grow hair. For instance, alopecia is a common dermatological condition and thought to be an autoimmune disorder that leads to some or all hair loss in the head or other parts of the body (Hunt & McHale, 2005). The prevalence of alopecia varies, and the approximate lifetime prevalence of the disorder is 1.7 percent in the United States (Hunt & McHale, 2005; Weitz, 2004). However, this estimate is not a reliable figure because few

epidemiological studies have been published (Hunt & McHale, 2005). To unpack assumptions around gender and hair, my research challenges dominant notions by examining femininity and baldness from the perspectives of women with alopecia areata, alopecia totalis, alopecia universalis, and monilethrix. In the following section, I describe these conditions. Although monilethrix is different from autoimmune alopecia areata disorders, my study includes monilethrix because I experience baldness from this condition beginning in infancy, and it initially inspires my research.

In general, a goal to my study is to promote an inclusive approach to female baldness by centering a conversation on women who experience baldness from alopecia areata, alopecia totalis, alopecia universalis, and monilethrix. Specifically, the main goal of this study is to historicize and examine the lived experiences of baldness from the perspectives of women with the aforementioned conditions within the larger context of female baldness, illness, and femininity. In sum, I examine medical and cultural discourses that prevail around female baldness and femininity. I consider the ways that women who experience baldness due to skin and hair conditions challenge hegemonic discourses through their bodies since these discourses uphold standards of femininity that assume specific styles, lengths and types of hair. Additionally, my study considers strategies of accommodation and resistance that bald women perform in a given context, space, or time. For example, one of the main aims of this study is to include an analysis on the participants' decision to wear a wig, turban, or bandana; bare her bald; manage eyebrows or eyelashes; or alternate between management strategies depending on the context and space. In certain contexts and spaces, participants change their typical management strategies based on hegemonic notions of femininity that hold participants accountable to performances of femininity.

For my study, I interviewed four women who are bald from alopecia areata, alopecia totalis, alopecia universalis, and monilethrix using an interactive approach. The interviews were analyzed for themes using interpretive phenomenological analysis, which is outlined in the methods chapter. Based on the analysis, I organized the information into two overarching themes that include (a) navigating the ideal femininity and (b) negotiating the assumptions of illness and female baldness. To begin, I provide a background with general definitions, descriptions, and histories about the four conditions included in my study. Next, I integrate literature from medical disciplines, social sciences, and gender studies in order to situate my study within the larger context on femininity, illness, and female baldness. Then, the following chapter outlines the theoretical frameworks and methodologies I used for my study. Following, I organize the discussion section into the two aforesaid themes where I provide participants' narratives and my analysis. To conclude, I examine limitations in my study and suggest areas of future research.

## **Chapter Two: Background and Literature Review**

### **Introduction to Background**

Because there are several types of alopecia disorders and the term is a general term or symptom to describe hair loss, I begin with a description of the general language around alopecia conditions and the three types of alopecia conditions that I include in my study (Mirmirani, 2007; Bray, Smith, & Elston, 2003; Hunt & McHale, 2005). Furthermore, alopecia areata has been adopted as the general umbrella term of autoimmune alopecia areata disorders and reflects some of the medical literature's use of the term (Alkhalifah, Alsantali, Wang, McElwee, & Shapiro, 2010; McKillop, 2010; Messenger, McKillop, Farrant, McDonagh, Sladden, 2012). In general, alopecia areata is a chronic, autoimmune, dermatological condition that results in hair loss (Alkhalifah et al., 2010; Hunt & McHale, 2005). However, alopecia areata also refers to one of the three sub-types of autoimmune alopecia areata conditions.

**Alopecia areata, alopecia totalis, alopecia universalis.** Alopecia areata, alopecia totalis, and alopecia universalis are the three levels of autoimmune alopecia areata conditions and are clinically classified based on the extent of hair loss (Alkhalifah, et al.). As the first level of autoimmune alopecia areata conditions, alopecia areata refers to patches of hair loss from the scalp (Alkhalifah, et al., 2010; Hunt & McHale, 2005). Alopecia areata can also affect a person's nails, a condition that accounts for ten percent of patients referred to specialists in the United Kingdom (Messenger et al., 2012). The second level is alopecia totalis, which refers solely to loss

of all hair on the scalp; contrastingly, alopecia universalis, the third level of autoimmune alopecia areata conditions, includes the loss of all head and body hair including eyebrows and eyelashes (Alkhalifah, et al., 2010; Hunt & McHale, 2005). Alopecia areata can, and oftentimes does, result in alopecia totalis and/or alopecia universalis. Particularly, alopecia totalis and alopecia universalis account for approximately 7 to 30 percent of all alopecia cases (Hunt & McHale, 2005).

Typically, alopecia areata conditions are asymptomatic and “medically benign” (Kalabokes & Best, 2001). However, some people report itching, burning sensations, or pain before hair loss begins (Alkhalifah et al., 2010). Alopecia areata conditions may leave individuals with emotional, social, and mental distress (Alkhalifah et al., 2010; Kalabokes & Best, 2001). For instance, people with alopecia areata are more likely to experience depression and anxiety (Cartwright, Endean, & Porter, 2009). Common experiences of autoimmune alopecia areata disorders are regrowth and relapse--making the course of the disease cyclical and unpredictable (Alkhalifah et al.; Kalabokes & Best, 2001). Following, I briefly discuss the history of autoimmune alopecia areata conditions.

***History of autoimmune alopecia areata.*** In 1896, Unna, a dermatopathologist who diagnose skin, hair, and nail conditions through a microscope, was the first to describe the “characteristic exclamation point hairs found in AA [sic]” (Kalabokes & Best, 2001, p. 340). He also stated that the course of the condition was chronic with “long remissions and rapid relapses” (Kalabokes & Best, 2001, p. 340). Still, alopecia areata research remained stagnant until the mid-1980s when the National Alopecia Areata Foundation (NAAF) began funding research grants and awareness campaigns through private donations (Kalabokes & Best, 2001). Nevertheless, research and general support for alopecia areata continues to be marginal

today. For example, health insurance companies in the United States do not cover hair and eyelash prosthetics or care for people with skin and hair conditions such as alopecia areata (Kalabokes & Best, 2001).

**Monilethrix.** Unlike autoimmune alopecia areata conditions, monilethrix is a rare, autosomal dominant hair shaft disorder (Bray et al., 2003; de Lencastre, 2012). Typically, the common symptom that presents the condition is “alopecia” or baldness because monilethrix causes the “affected hairs to become brittle, dry, and lustlerless, with a tendency to fracture spontaneously from mild trauma” (Bray et al., 2003, pp. 453-454). Mostly, it is the scalp hair that is affected, but it can affect other parts of body hair. Similar to alopecia areata, monilethrix can cause fragile nails. Additionally, 90 percent of patients with monilethrix have keratosis pilaris, which is also asymptomatic, but cosmetically appears by affecting hair follicles under the skin (Bray et al.). Interestingly, keratosis pilaris on the neck is an indicator of the condition, but most commonly family history or microscopic confirmation reveals the condition (Bray et al.; de Lencastre & Tosti, 2012; Leitner et al., 2013). Monilethrix usually presents itself during infancy, but it can appear later in life (Bray et al.). Furthermore, there is no effective treatment for monilethrix. Research states that for some the condition improves with age, during pregnancy, or after puberty, but for others, it remains present throughout life (Bray et al.). Research also suggests that avoiding trauma to the hair can cause growth (Bray et al.).

***History of monilethrix.*** Although the information on the history of alopecia areata is minimal, the information on monilethrix is even scarcer. Monilethrix was first described by Walter Smith in 1879, but it was later given its coined name at a date which I was unable to find during my research (Bray et al., 2003). Fittingly, *Monile*

is Latin for necklace, and *thrix* is Greek for hair (Bray et al., 2003; de Lencastre & Tosti, 2012). Throughout its history, genetic studies have been conducted to find the specific location of the gene, but there are no conclusive studies (Bray et al.). The brief history reflects the limited literature and knowledge that I found on monilethrix.

### **Introduction to Literature Review**

For this section, I shift from the history and language around the skin and hair conditions to the existing literature surrounding autoimmune alopecia areata conditions and monilethrix in order to situate my study within the medical and cultural discussions of female baldness, femininity, and illness.

### **Medical Literature**

Scholars in the social sciences have done little research on women who are bald from skin and hair disorders. When there are discussions of disorders such as autoimmune alopecia areata conditions and monilethrix, it exists predominately within medical disciplines. Since there are several types of alopecia, I found that medical research on alopecia disorders focuses disproportionately on androgenetic alopecia (also known as male or female pattern baldness) (Mirmirani, 2007; Monselise et al., 2013; Price, 2003, Singal, Sonthalia, & Verme, 2013; Sinclair et al., 2011; Thomas, Price, & Savin, 1993). Androgenetic alopecia is the most common cause of hair loss or hair thinning, and it expresses itself to some degree regardless of sex by the age of 50 (Price, 2003). Perhaps, the prevalence of androgenetic alopecia influences the medical discipline to focus on androgenetic alopecia, rather than explicitly focusing on baldness from other forms of alopecia. Therefore, my research shifts the focus to other forms of alopecia in hopes of promoting the inclusion of autoimmune alopecia areata disorders, monilethrix, and other conditions that cause baldness in the discussion. Research on

monilethrix is scant and leads me to focus more on the literature about alopecia. Nevertheless, I extend some of the literature around alopecia to experiences of monilethrix.

**Chemotherapy-induced alopecia.** In addition to focusing on androgenetic alopecia, research exemplifies a disproportionate attention to chemotherapy-induced alopecia and baldness (Batchelor, 2001; Borsellino & Young, 2011; Carver et al., 1998; Chen et al., 2011; Cohen, Kahn, & Steeves, 1998; Denieffe & Gooney, 2011; Erol, Can & Aydmer, 2012; Frith & Harcourt, 2007; Helms, O’Hea, Corso, 2008; Jayde, Boughton, & Blomfield, 2013; Lemieux, Maunsell, & Provencher, 2008; Rosman, 2004; Williams, Wood, & Cunninham-Warburton, 1999; Zannini et al., 2012). This scholarly trend is consistent with the current cultural inclination toward reproducing an institutionalized commodification of cancer awareness specific to breast cancer and female bodies in this historical time and society (King, 2001; Klawiter, 2008). Ultimately, the hypervisibility of chemotherapy-induced alopecia reifies the association of baldness with illness and death. When baldness is reduced to illness and death, negative representations of baldness potentially exclude or disempower individuals who do not view their baldness as an illness or negative attribute. For some, baldness has become part of their identity and/or continues to change one’s identity, and these stories deserve inclusion. Regardless of the imbalance of attention, the literature on androgenetic alopecia and chemotherapy-induced alopecia does provide insight to shared experiences of hair loss and baldness in relation to autoimmune alopecia disorders and monilethrix.

In a literature review on chemotherapy-induced alopecia, Lemieux et al. (2008) found that, for women with breast cancer, chemotherapy-induced hair loss is the most significant side effect of chemotherapy and can lead to refusal of chemotherapy.

Additionally, women with breast cancer describe hair loss from chemotherapy as traumatizing and a cause for distress (Lemieux et al.; 2008). The literature around chemotherapy-induced baldness also implies that hair loss may impact body image, but not all studies include this finding (Lemieux et al.). However, for some, the perception of chemotherapy-induced alopecia is positive and their alopecia is a sign of the effectiveness of chemotherapy (Lemieux et al.). Demonstrating the complexities and spectrum of lived experiences that women facing hair loss and baldness experience, Lemieux et al.'s research exemplifies the intersection of gender, hair, and baldness. Although these experiences of chemotherapy-induced baldness are important, the literature around alopecia disorders and female baldness in general could benefit from a more holistic approach in order to distance the cultural attribution of illness and female baldness.

**Alopecia areata.** When discussions of alopecia are outside of chemotherapy and androgenetic alopecia, the focus is on alopecia areata (referring to the first level of autoimmune alopecia areata conditions) and issues of treatment (Alkhalifah, Alsantali, Wang, McElwee, & Shapiro, 2010); support (MacDonald, 2007); the psychological impact of the disorders (Monselise et al., 2013; Tülin Güleç et al., 2004); and the comorbidity of psychiatric disorders (Ghanizadeh, 2008). In other words, the consideration of the emotional and social impact of these conditions and female baldness is absent in medical literature. Even more so, the explicit discussion of alopecia totalis and alopecia universalis is nominal, though, the use of alopecia areata as an umbrella term to encompass all three subtypes may be a factor contributing to the scarce findings on alopecia totalis and alopecia and universalis.

When medical conversations examine the quality of life and psychological impact for people with alopecia, it is through questionnaire-based methods (Cartwright, Endean, & Porter, 2009; Monselise et al., 2013; Tülin Güleç et al., 2004). For example, Cartwright, Endean, and Porter (2009) assessed the relationships between illness perception, coping, and quality of life (QoL) in people with alopecia. For their research methods, Cartwright et al. (2009) employed an online questionnaire that consisted of the Revised Illness Perception Questionnaire, the Dermatology Life Quality Index, and the brief COPE assessment—three quantitative assessments potentially producing standardized information amongst participants. The methodological approaches provide insight on the effects of alopecia areata, but reflect the medical discipline’s scientific and quantitative approaches to research. These approaches do not necessarily assess the needs and desires of people with these conditions. Therefore, the general discussion around baldness from skin and hair disorders could benefit from examining and analyzing the lived experiences from the voices of the people who have the conditions.

### **Literature on Hair and Baldness**

As the above section suggests, the literature specific to autoimmune alopecia areata conditions and monilethrix exists vastly within medical research. However, there are historical discussions within social sciences and other disciplines that examine hair and baldness. For instance, in this section, I include literature that analyzes the symbolisms and public interpretations of hair and baldness throughout history in this society. I include these discussion in my study because they demonstrate cultural and historical assumptions about hair and baldness.

**Symbolism of hair and baldness.** As previously noted, social scientists and anthropologists provide knowledge on the public and historical symbolism of head hair, body hair, and baldness throughout various cultures and societies (Duncan & Derrett, 1973; Firth, 1973; Hallpike, 1969; Hershman, 1974; Leach, 1957; Synnott, 1987). For instance, Hallpike (1969) expands on Leach's (1957) psychological theory that considers whether head hair symbolizes sexuality across societies. Hallpike disagrees with Leach's theory but contends that cutting hair equals social control and suggests that "dressing the hair" may also be "ceremonially equivalent to cutting it" (Hallpike, 1969, p. 261). Following Hallpike, Firth (1973) continues the discussion of social symbolism in relation to hair and recognizes the symbolic differences of hair pertaining to women and men. In particular, Firth (1973) analyzes the symbolism of hair loss, baldness, and shaving of the head. Since the cultural symbolism of the length of hair has been historically associated with positive values, by default, hair loss and shaving the head are negative and deviant (Firth, 1973). Specifically, Firth (1973) describes a dialectical relationship associated with the symbolism of cutting hair and personality changes. Accordingly, the loss of hair symbolizes the reduction of personality; whether it is from nature and aging and/or artificial by human through an alteration in personality (Firth, 1973). These historical texts are beneficial to my research when considering the cultural narratives and symbolism of baldness, but, for the most part, the dialogue around baldness and the analysis of gendered significance of hair and baldness is minimal.

**Public interpretation and social movements.** Firth (1973) also examines how hair challenges the public and private divide. Assumptions of hair include that hair is part of the body and is personal to that body; however, the salience of hair allows for it to be open to public interpretation and symbolism (Firth, 1973; Synnott, 1987; Weitz,

2004). Consequently, hair has served as a tool of politics and resistance (Synnott, 1987; Weitz, 2004). To illustrate, “hippies,” in the 1960s and 1970s, created a middle-class, political social movement with distinct symbols of protest and one of these forms included hair. Against social norms of the time, women who were hippies wore their hair long and “natural” without dyes, extensions, wigs, and maintenance, whereas men who were hippies grew their hair long with moustaches and beards. These styles were considered against the norm and thus challenged professionalism and the traditional, hegemonic, white middle-class expectations of the time (Synnott, 1987). In another example, dreadlocks originate from Jamaican Rastafarians and therefore have a specific cultural, political, and spiritual historical association (Weitz, 2004). Similar to these examples, baldness symbolizes political movements and messages regardless of the intention or reasoning.

Throughout history, baldness denotes a spectrum of political, social, and religious movements. This spectrum ranges from general youthful rebellion, feminism and lesbianism to Monks, and “skinheads” (Hillman, 2013; Synnott, 1987; Weitz, 2004). Particularly, in the United States during the women’s movements of the 1960s and 1970s, some feminists practiced cutting their hair short as a way to reject traditional roles and expectations of attractiveness (Hillman, 2013; Firth, 1973; Weitz, 2004). These hairstyles coupled with feminist beliefs that challenged notions of femininity, masculinity, and heterosexuality helped create the shorthaired, man-hating, lesbian, misandrist-feminist stereotype. Subsequently, in contemporary society, this monolithic, stereotype of feminists and lesbians associates short hair, buzz cuts, and baldness on female bodies to feminism and lesbianism. Therefore, it is imperative to examine and

situate these historical public interpretations and symbolisms in relation to participants' experiences of baldness.

### **Situating My Study**

While the previous section provides insights on public interpretations of hair and baldness, the literature does not necessarily include explicit analysis of gender and female baldness. In order to situate my study within ongoing discussions of dominant beauty ideals, femininity, and hair, I shift the focus to feminist scholars and scholars from various disciplines who focus on the intersection of hair with axes of life such as gender, race, ability, and class.

**Feminism, hair, and baldness.** Scholars continue to engage in a plethora of conversations regarding the construction of femininity and beauty ideals in regards to hair and hairlessness. Oftentimes, these conversations discuss hair as a site of resistance or accommodation to one's identity and the expectations of the ideal femininity given context, space, and time (Bartky, 1990; Weitz, 2001; 2004). Particularly, research considers the ways that discourses and societal expectations of the workplace, policy, beauty salons, and social movements aid in perpetuating and resisting the construction of femininity in the United States today (Black & Sharma, 2001; Hillman, 2003; Onwauchi-Willig, 2010; Weitz, 2001; 2004). The expectations of appropriate hairstyles for professional women reify the feminine ideal as the standard and render whiteness as normative (Onwauchi-Willig, 2010; Weitz, 2001; 2004). Due to this, Black women's hair and hairstyles are deviant, unprofessional, and not appropriate for the workplace.

**Black femininity and hair.** When discussing the significance of hair to female bodies, one must incorporate a great deal of research that recognizes the importance of hair in African American communities. Because I historicize women's experiences of

baldness, I integrate experiences of women who have multiple subjectivities as well as literature that centers these multiple subjectivities of women's lives. Specifically, the inclusion of Black feminist literature on hair complicates the idea that the female body is reducible to the hegemonic feminine ideal. Thus, it is crucial to integrate research on the experiences of female bodies that fall outside dominant notions of femininity.

Oftentimes, Black women produce research in order to historically situate their experiences and relationships to hair as critiques and limitations to Eurocentric, white ideals. Specifically, these conversations include discourses of femininity outside of dominant ideals, notions of resistance and accommodation, internalization, and lived experiences of having hair that discourse defines as "deviant" in the United States (Banks, 2000; Byrd & Tharps, 2001; Craig, 2002; Davis, 1974; Green, 2011; Patton, 2006; Thompson, 2008; 2009). For instance, Patton (2006) uses standpoint theories and Afrocentric theories as frameworks to reveal issues within the dominant Eurocentric standards of beauty with the possibility of redefining standards of beauty and "normality." Through sharing and centering women's multiple subjectivities and lived experiences surrounding their subjectivities, we unpack hegemonic notions of hair and femininity that privilege whiteness.

**Hairlessness and body hair removal.** Social science literature that focuses on hairlessness limits hairlessness the absence of body hair as opposed to absence of hair on the head (Synnott, 1987; Toerien & Wilkinson, 2003). Within contemporary Western culture, body hair removal is a normative practice, which operates within the feminine ideal (Toerien & Wilkinson, 2003). As an example, the history of hypertrichosis has been defined as excessive hairiness and has been culturally represented through images of bearded women (Herzig, 2000). The normative

expectation within the United States of the absence of body hair on the female body contributes to the stigmatization of women with hypertrichosis and allows this condition to define one's sexual identity. Prior to 1930, hypertrichosis was partially defined by a confusion of sex appearances. After the 1930s, discussions around sexual identity and hypertrichosis determined normal female identity based on the patient's level of desire for hairlessness (Herzig, 2000). In other words, a person with hypertrichosis who did not desire hairlessness was defined during this time as not woman. This literature on hypertrichosis unpacks the historical and cultural significance of body hair removal practices in the United States (Herzig, 2000).

In the disciplinary practices of body hair removal, the underlying assumption that exists suggests that a female body is unacceptable if left unmaintained (Toerien & Wilkinson, 2003). Paradoxically, the ideal femininity requires hairlessness of body hair while requiring hair on the head. Nevertheless, both require a degree of maintenance. These practices and cultural assumptions are important to examine from the experiences of women who are bald from autoimmune alopecia areata disorders and monilethrix because the absence of hair on the head and body parts expose these contradictory narratives. Although body hair removal is a normative practice in the United States within the construct of femininity, eyelashes and eyebrows are requirements of a female body. Despite these societal beliefs, the physical symptoms of autoimmune alopecia areata disorders and monilethrix challenge norms and expectations of femininity merely by existing.

**Weitz and baldness.** Significantly, one feminist scholar dedicated extensive time and research to the lived experiences of "women and their hair" (Weitz, 2001). In *Rapunzel's Daughters*, Weitz (2004) includes a detailed historical analysis of the

relationship of women with their hair or hairlessness. Weitz adopts an intersectional approach to women's experiences of hair, and the inclusion of women who do not have hair exemplifies this intersectional approach. In the chapter "Bald Truths," Weitz discusses baldness ranging from hair loss through alopecia, chemotherapy-induced baldness, and personal choice (Weitz, 2004, p. 134). The experiences of women who are bald include topics such as management strategies, psychotherapy, relationship issues, bullying, lack of self-confidence, the cost of hiding hair loss, and the anxieties associated with wearing a wig. As a woman who experiences baldness from monilethrix, I never related to experiences involving hair and femininity as considerably as I did when reading this chapter, specifically the section on alopecia. As I interpret it, this is the significance of Weitz's entire book—to expose the taken-for-granted daily assumptions about women and hair. The purpose of my research is to continue this conversation about women's baldness and to center this discussion on baldness from skin and hair disorders.

**Management techniques.** In addition to sharing women's experiences of hair and baldness, Weitz troubles past scholarship that suggests baldness is more detrimental for men (Synnott, 1987). Weitz (2004) states, "while for men 'comb-overs' and toupees remain more stigmatized than sporting a bare or balding head, almost all balding women conclude they have no socially acceptable choice but to hide their hair loss" (p. 137). Unfortunately, the stigmas associated with baldness often reify societal expectations that women must conceal their baldness and alter their bodies. Consequently, some women hide their baldness because they are compelled by the hegemonic ideal femininity. Throughout time, women who are bald have discovered several ways to manage their baldness outside of wearing a wig, such as wearing a

turban and showing off their baldness. Still, the research around management techniques focuses disproportionately on wigs (Cooper, 1971; Derrett, 1973; Firth, 1973; Leach, 1957; Synnott, 1987; Zannini et al., 2012). Particularly, research examines wigs in the context of religious symbolism, ritual practices of covering hair, and historical symbolism that Cooper (1971) describes as badges and disguises (Derrett, 1973; Firth, 1973; Leach, 1957; Synnott, 1987; Weitz, 2004).

Research beyond wigs is minimal in relation to management techniques, especially management strategies for eyebrow and eyelash loss. This absence is problematic because alopecia areata conditions affect more than just head hair. However, I recognize that the lack of focus on autoimmune alopecia areata conditions may contribute to this gap (Mirmirani, 2007).

In relation to research on management techniques explicit to autoimmune alopecia areata conditions, research focuses on potential medical “treatment” options (McKillop, 2010; Messenger et al., 2012). According to McKillop (2010), treatment typically falls into two categories, which include an attempt to “stimulate the hair follicles and/or to suppress the immune system” (p. 44). On the one hand, corticosteroid shots are used to suppress the immune system (McKillop, 2010). On the other hand “topical immunotherapy” methods, such as diphencyprone (DPCP) or psoralen plus ultraviolet A (PUVA), create an allergic reaction (DPCP) or expose ultraviolet radiation (PUVA) to stimulate hair growth (McKillop, 2010). Despite this, the information reads as “how to” guides and informational tools for medical professionals to discuss amongst themselves. I recognize this knowledge potentially reaches patients, but it does not examine the needs and desires for management techniques from the

voices of the women who have these conditions (McKillop, 2010; Messenger et al., 2012; Mirmirani, 2007).

**Counseling and psychological treatment.** Research recognizes and examines the presence of psychological and emotional impact of alopecia areata conditions; however, the research on psychological treatment effectiveness is absent (McKillop, 2010; Messenger et al., 2012). In Hunt and McHale's (2005) review of research on the psychological impact of alopecia, they contend that doctors should be aware of the psychological impact of alopecia—especially since medical treatments have limited effectiveness. Suggestively, Hunt and McHale outline the significance of considering how providing ineffective treatment could potentially exacerbate the psychological impact of these conditions. Moreover, Hunt and McHale (2005) conclude that doctors should help patients understand their alopecia and their psychological responses to the condition as well as provide *appropriate* information about changing their appearance. In order to achieve the designation of appropriate information, I argue, this discussion should include the co-construction of knowledge between doctors, patients, researchers, and the women who experience these conditions.

**Qualitative approach to women's experiences with baldness.** As the above suggests, there is insufficient research that assesses the lived experiences of people living with baldness from skin and hair disorders. One of few studies that exist consists of interviews with people living with alopecia areata and alopecia universalis in order to assess a more holistic approach to the psychological impact of these disorders (Welsh & Guy, 2009). Welsh and Guy (2009) conclude that future research should focus on each particular sub-type of alopecia to consider the “divergence of lived experience between different types of alopecia” (p. 200). My study analyzes women's experiences

with alopecia areata, alopecia totalis, and alopecia universalis as well as other conditions, such as monilethrix. Although I consider these conditions in relation to one another, I recognize and analyze the differences between sub-types of alopecia. Additionally, Welsh and Guy (2009) conclude that future research should focus on the gendered experience of alopecia areata and universalis. My research considers the gendered experience and embodiment of hairlessness and hair loss caused by alopecia areata, totalis, universalis, and monilethrix and therefore fills that gap. In the next chapter, I discuss the theoretical frameworks and methodologies used in my study.

## **Chapter Three: Theoretical Framework and Methods**

### **Introduction to Theoretical Framework**

Due to the interdisciplinary approach of my research, I integrate theories from a multiplicity of theorists and disciplines. Specifically, my theoretical framework extracts theories from feminist, sociology, and disability scholars in order to unpack hegemonic assumptions of female bodies, femininity, and illness. In the following sections, I discuss how my theoretical framework relates to experiences of female baldness from skin and hair disorders.

### **Feminist Theories**

My research draws on literature by foundational feminist theorists, such as de Beauvoir (1974) and Wittig (1980), which focus on the social construction of the category “woman.” Both theorists claim that the “myth of woman” naturalizes the category itself (de Beauvoir, 1974; Wittig; 1980). The social construction of woman is significant when analyzing experiences of female baldness because hair has been a historical signifier of “woman.” Therefore, women who are bald from skin and hair disorders challenge claims that hair is an attribute of femaleness.

In addition to social construction theories, I use Hartsock’s historical materialist approach to feminist standpoint epistemology, which contends that women are more likely to understand the knowledge of their condition and the knowledge of their oppressor (Hartsock, 1983). Hartsock states that we are embodied humans consisting of both the natural and the social. She also recognizes that for important strategic reasons,

feminists are more attentive to the social; and therefore, Hartsock argues for feminists to adopt “historical materialist approach to understanding phallographic domination” (1983, p. 216). However, Hartsock acknowledges that not every woman has the same experience, and she contends that there are historically situated expectations of what female bodies are supposed to do and be in a society. In relation to my study, baldness is not an expectation of a female body—quite the opposite, actually. Therefore, I adopt Hartsock’s approach and extend it to women who are bald from skin and hair disorders. If societal expectations of female bodies constitute shared experiences for women, then, women who are bald from skin and hair disorders also have similar, shared lived experiences because their female baldness position them outside of historical expectations of female bodies.

Similar to Hartsock, Scott’s “evidence of experience” recognizes the political motivation behind experiential knowledge, but distinguishes that there are limitations when solely using experience as knowledge (Scott, 1993). Scott argues that the evidence of experience reproduces ideological systems. To illustrate, I share experiences of female baldness through the voices of the subjects themselves. While making female baldness present through women’s voices is an important project, it also is important to historicize participants’ experiences while critically examining the ideological systems that produce these experiences. If I neglect to historicize experiences, my analysis risks reproducing ideological systems because, ultimately, we are left with knowing differences exist but not the construction of differences (Scott, 1993). Scott states, “it is not the individuals who have experience, but subjects who are constituted through experience” (p. 401). In other words, subjects become constituted through their shared, historical experiences, which produce limited choices (Scott). Therefore, choice exists,

but there are limits to these choices depending on historical context. I aim to use Hartsock's and Scott's ideas to historicize and analyze the lived experiences of women who are bald from skin and hair disorders with hopes to unpack the shared experiences and choices surrounding female baldness.

**Gender as performative.** As aforementioned, my research assumes that gender is not essential, but instead performative (Butler, 1990). For Butler, the notion of gender only exists through social performances; and therefore, gender is not natural and can be changed or disrupted. When Butler (1990) states that gender is instituted outside of the body through a continual process, this means it is specific to the social context of one's sex, gender, race, and sexuality. Furthermore, Butler argues that the disciplinary practices of bodily gestures and movements create an illusion of "an abiding gendered self," which refers to the naturalization and normalization of gender (Butler, 1990, p. 421). Butler contends that the acts and gestures attributed to gender produce the effect of an internal essence, and the performance of these acts and gestures itself creates a naturalized, gendered identity (1990, p. 417). In other words, gender attributes are not expressive of a true gender identity, but express the performance and therefore the attributes constitute the abiding gendered self. Thus, gender attributes, such as hair, do not belong to a true gender identity and cannot be measured as expressing a true gender identity. However, there are punitive consequences for not "appropriately" performing gender in a society compelled by the perceived naturalness of gender, and these material realities cannot be ignored in theory. Ultimately, Butler argues that transformation is made possible in the failure to repeat these stylized acts (1990, p. 421). In relation to my study, theories on the performativity of gender is significant because baldness from skin and hair disorders are in/of the body and female baldness does not adhere to the

constructed notions of femininity. For my research, the materiality of the body “matters” because female bodies that are bald potentially expose the social construction of gender by challenging hegemonic notions of femininity by merely existing. The experiences of women who are bald from conditions within the body challenge and expose the illusion that dominant discourse maintains and reproduces about a true gender identity (Butler, 1990). Moreover, women who are bald have the potential to challenge or resist hegemonic notions of femininity through performing and/or disrupting the stylized repetition of acts.

**Feminism and Foucault.** Foucault’s notion of power/knowledge and disciplinary discourse is significant when examining how structures such as medicine, media, and religion institutionalize power onto bodies through discursive regimes that constitute the docile, disciplined body (Foucault, 1979). Throughout the course of Foucault’s career, he shifts his discussion from examining systemic power onto bodies to acknowledging that with power comes resistance (Foucault, 1983). Although Foucault recognizes that disciplined bodies can still resist these disciplinary practices, he also argues that this resistance may reify dominant ideologies. Foucault’s definition of power/knowledge and understanding of resistance is beneficial to the present study because the institutionalization of medical, media and cultural discourses onto disciplined bodies exposes how these disciplinary practices normalize and perpetuate discursive power and the naturalness of the docile body. For my study, I examine how women who are bald from skin and hair disorders may simultaneously resist and reinforce hegemonic notions of femininity through their bodies, hair, and baldness. Nevertheless, Foucault’s work does not exist without critique. For example, a feminist critique of Foucault is that he does not differentiate between the embodied experiences

of female bodies and male bodies (Bartky, 1990; Bordo, 1993). For Bordo, this absence of difference ignores women's bodies as a historical place of politics and denies that personal liberation has the potential for cultural transformation. I integrate these feminist critiques and uses of Foucault in the following discussions.

In "Foucault, Femininity, and the Modernization of Patriarchal Power," Bartky (1990) contends that Foucault treats the body as if it is one. Accordingly, Foucault does not account for the specific disciplinary practices and bodily experiences that produce the feminine docile body. Specifically, Bartky (1990) analyzes how women internalize this "state of conscious and permanent visibility" (p. 65), which refers to Foucault's theory of surveillance and self-surveillance. This internalization is apparent through the docile body's constant self-surveillance and through the disciplinary feminine bodily practices. Similar to de Beauvoir, Wittig, and Butler, Bartky (1990) argues that femininity is an artificial construct and that the distinct, disciplinary practices produce feminine docile bodies. Bartky (1990) divides these practices into three categories that create docile bodies that: appears a certain size and configuration; performs specific gestures, postures, and movements; and presents this body as an ornamented surface. For my research, the category that produces bodies as an ornamented surface is the most relevant because it examines bodily practices surrounding hair. In the essay, Bartky (1990) asserts that women have acquired a specialized knowledge based on the training of make-up application, hairstyling, and certain hair products. Although this specialized knowledge includes hair practices, it does not include hairlessness on the head. In particular, the feminine ideal only considers hairlessness on female bodies in the context of body hair. While hegemonic discourses of femininity assume that women have hair (and even a certain type of hair), I extend the notion of specialized knowledge

to women who are bald from skin and hair disorders when managing their conditions in accommodation and/or resistance to the feminine ideal. On the one hand, I consider whether there is a specialized knowledge that bald women gain through the experiences that constitute them as docile bodies outside the norms of ideals of femininity. On the other hand, I examine whether female baldness limits participants of acquiring the specialized knowledge that ideals of femininity produce for and project on the feminine docile body.

Bartky (1990) recognizes the intersecting systems of oppression in women's lives and how these various stratifications shape disciplinary practices; however, Bartky's theory focuses more on patriarchal power in relation to hegemonic ideals of femininity and limits discussions that include race, class, and sexuality. Therefore, I expand on Bartky's discussion of intersecting systems of oppression by examine the influence of other forms of structural power such as capitalism, racism, heterosexism, and ableism in relation to the construction of femininity. For example, as a woman who is bald and comes from a lower socioeconomic status, I recognize the role of patriarchal power, whiteness, institutionalized heterosexuality, and capitalistic power in my "decision" to wear a wig. Although I cannot claim or universalize the same for all women who are bald, my experience of baldness and my positionality influences my analysis to include other institutional forms of power.

Another important scholar who incorporates Foucault and feminism is Susan Bordo. Bordo (1993) argues that we should not assume women are cultural dupes or victims. This argument means that we must examine the ways we perpetuate our own subjectivity, but to assume resistance does not exist is equally problematic. For feminist scholars in particular, the discursive turn and the effects of this turn leads Bordo to

critique feminism's overappropriation of Foucault's postmodern ideas about resistance. As noted, Foucault's later work recognizes that where there is power, there is resistance, but he goes on to argue that normalization is still the dominant discourse. However, for Bordo, our docility as female bodies can have effects that are personally liberating and can be simultaneously culturally transforming (Bordo, 1993). Bordo's understanding of power reminds us that, for Foucault, power is constitutive and that the presence of power does not mean the absence of pleasure.

Hegemonic discourses that produce the feminine ideal allow for the eruption of 'difference' and therefore even the most subordinated subjects are continually confronted with opportunities for resistance and for making meanings that 'oppose or evade the dominant ideology'" (Bordo, 1993, p. 255). Through this understanding of Foucault, feminists resituate Foucault when we incorporate the earlier, Marxist Foucault who interrogates the "grip" of systemic power onto the body, and the postmodern Foucault who considers how bodies resist that grip (Bordo, 1993, 255).

Considering the development of Foucault's ideas as presented by Bordo, one can begin to understand the power and pleasure of being different in this culture while also recognizing that difference may reify dominant ideology. Nevertheless, Bordo resituates the importance of the body as a political space that can be used as a site of resistance. My study aims to consider ways women who experience baldness from skin and hair disorders simultaneously reify and resist hegemonic discourses of femininity through their bodies. My research also seeks to listen to women who are bald from skin and hair disorders to consider the ways they make their own empowering meanings of being "different" and, in particular, the ways they use their body to resist hegemonic discourses of femininity. For bald women, wearing a wig, exposing one's bald, wearing a

turban and/or alternating between management strategies depends on context and may be personally liberating to participants despite whether they reify dominant ideologies or not.

### **Disability Theories, Illness Narratives and Coming Out Narratives.**

Given my experience and knowledge as a woman with baldness, I consider how knowledge and theories of disability, illness, medicalization and coming out can be beneficial to the analysis of women's experiences and narratives of baldness. While I do not claim that baldness is a disability or an illness, cultural assumptions reduce female baldness to understandings of illness. For example, a hypervisible cultural narrative of female baldness is that it is chemotherapy-induced. Furthermore, participants' experiences with their conditions, such as onset of condition, narratives of loss, and their experiences with managing their conditions prompts me to include theories of medicalization, illness, and coming out.

**Medicalization theories.** Medicalization theories reflect the ways that human conditions become historically and socially constructed into treatable disorders (Conrad, 2007). Similar to Riessman's (1983) work on the medicalization of women's reproductive functions, I believe that baldness on female bodies is a human condition that has been medicalized while still recognizing that some baldness conditions prompt medical intervention. However, medical research regarding skin and hair conditions, specifically alopecia conditions, focuses on treatment such as corticosteroid shots, medication, and creams that have questionable effectiveness at best (Alkhalifah, Alsantali, Wang, McElwee, & Shapiro, 2010; Hunt & McHale, 2005). Simultaneously, medical research fails to holistically consider the psychological, emotional, and social support that people with appearance-altering conditions, such as alopecia disorders and

monilethrix potentially desire or need (Alkhalifah et al., 2010; Cartwright, Endean, & Porter, 2009; Hunt & McHale, 2005; MacDonald, 2007; Monselise et al., 2013; Tülin Güleç et al., 2004; Ghanizadeh, 2008). Paradoxically, Rosich and Hankin (2010) discuss that defining a physical condition as an illness or disease has consequences for access to treatment, the health care system, stakeholders such as the pharmaceutical industry, and social legitimacy. As of now, alopecia areata, totalis, universalis, and monilethrix are not curable and are typically medically benign, but female baldness is a human condition that is socially and historically abnormal for a female body. Therefore, theories of medicalization may be useful when analyzing participants' experiences and interactions with the medical industry.

**The sick role.** Autoimmune alopecia areata disorders and monilethrix are chronic conditions; as a result, discussions around Parsons's (1975) sick role and Varul's (2010) critique of the sick role in relation to chronic illnesses are relevant. Again, I do not necessarily claim that people with skin and hair disorders, are "sick" or "ill," but the medicalization of the condition invites this consideration because participants' may become diagnosed with the condition depending on the age of onset.

Varul applies Parsons's (1975) sick role for individuals with chronic illness, and asserts that in these cases the sick role means that people with chronic illness are under the control of the medical system, full capacity of health cannot be recovered, and the motivational component to recovery may be controlled (Varul, 2010). Furthermore, Varul contends that through the process of normalization the chronically ill become dual citizens of illness and health. By the process of normalization, Varul refers to a process where the patient seeks normalcy despite their diagnosis of a chronic condition. Recognizing that normalization is not fully attainable for the chronically ill as there is no

cure, Varul argues illness becomes an occupation. Parsons argues that the physician/patient relationship is asymmetrical; Varul does not refute this asymmetry, but Varul states that power differentials for the chronically ill have the potential to change and therefore expectations for treatment may change. Although eradication of illness is not achievable, individuals must self-monitor, manage, and follow a regimen so they do not overcompensate their illness or health (Varul, 2010).

Shifting the discussion, Varul concludes with a conversation on chronic health and contends that these preventative measures shifts responsibility to the individual. The notion of chronic health and preventative measures reflects ideologies of a neoliberal, individualistic society, such as the United States, which can shift blame of illness from the medical institution to the individual. Furthermore, the hypervisibility of female baldness associated with chemotherapy-induced alopecia creates the pervasive association of baldness and illness--adding to the invisibility and erasure of other narratives of baldness. For my research, I attempt to understand how women with alopecia areata, totalis, universalis, and monilethrix circumnavigate the sick role and narratives of illness. It is imperative to analyze the ways that women with alopecia areata disorders and monilethrix accommodate and reject illness identities, roles, and narratives based on context, needs, and desires.

**Restitution, chaos, and quest narratives.** In “The Wounded Storyteller: Body, Illness, and Ethics,” Frank (2006) describes three types of illness narratives including restitution, chaos, and quest narratives. The restitution narrative assumes that the illness can and will be cured; whereas, the chaos narrative is opposite of this narrative in that there is no predictable ending (Frank, 2006). Lastly, the quest

narrative approaches illness as a journey where the individual is a hero who is taking ownership over their illness (Frank, 2006).

My research incorporates experiences of baldness from various types of conditions, and participants' conditions and understanding of their condition create differences in participants' shared experiences and the ways participants tell their story. On the one hand, participants' lived experiences with alopecia areata, alopecia totalis, and alopecia universalis differ from the experiences of monilethrix because there are differences in the ages of onset. For example, due to this difference in the age of onset, there may be narratives of loss that exist with participants who have autoimmune alopecia areata conditions, which do not necessarily exist with the participant who has monilethrix. On the other hand, participants' experiences with alopecia areata, alopecia totalis, and alopecia universalis differ from one another because each condition comes with new circumstances and life experiences due to the differences in conditions and other aspects of life. Although I am interested in extracting common themes amongst participants' experiences with baldness, I consider and reflect when differences appear, especially in relation to illness narratives and narratives of loss.

**Coming out narratives.** As discussed, a cultural historical assumption about what constitutes a female body equates hair with womanhood; therefore, a female body without hair may be perceived as not woman, the Other, deviant, ill, dying, and disabled. This assumption reifies expectations of the ideal feminine body and does not account for female bodies or women who are bald from the physical body, such as alopecia areata, totalis, universalis, and monilethrix. Due to these societal expectations, women who are bald from skin and hair disorders are potentially negotiating identities, coming out,

passing, and hiding depending on context (Samuels, 2003; Sedgwick; 1990; Sedgwick, 1994).

Although I do not claim these conditions are disabilities, I follow previous scholars who have consider theoretical narratives of coming out within sexuality and disability studies (Samuels, 2003; Sedgwick; 1990; Sedgwick, 1994). By way of illustration, Sedgwick (1994) discusses how her experience with breast cancer and illness during 1991 was influenced by much of the work done in the 1980s by AIDS activists. Particularly, Sedgwick (1994) reflects on the “dialectical epistemology” of the two illnesses, and states “the kinds of secret [sic] each has constituted; the kinds of *outness* each has required and inspired – has made an intimate motive for me” (pg. 155). It is the dialectical epistemology of these narratives that is useful for my research and leads me to consider how coming out narratives can be extended to help understand and analyze women’s lived experiences of baldness from skin and hair disorders. Inadvertently, Sedgwick (1994) “warmly encourages anyone interested in the social construction of gender to find some way of spending half a year or so as totally bald woman” (pg. 153). Though similar to Samuels (2003), I am extremely critical in making connections and analogies of experience, oppression, and liberation based on sameness- especially in a society that strategically uses the rhetoric of sameness and equality as an oppressive tool of erasure. As a result, when discussing women’s experiences of baldness in relation to coming out narratives, I am reflexive and do not make generalizations or metaphors across experiences of oppression and liberation.

### **Introduction to Methods**

For my study, I use the methods of interactive interviewing and interpretive phenomenological analysis. In the following sections, I define these two methods and

discuss how they relate to my study. Additionally, I describe the participant recruiting process and discuss the final sample of participants.

### **Traditional Interviewing**

In general, interviewing is a qualitative method of research that various disciplines use to conduct research. Traditionally, interviewing is unappealing for feminist scholars in the sense that it has been structured in a hierarchical, masculine paradigm (Oakley, 1981). There are methodological problems to interviewing for feminist researchers because interviewing elicits a hierarchy where the interviewer receives but does not give information (Oakley 1981). Furthermore, traditional interviewing views the interviewee as data and interviews are seen as impersonal interactions in order to maintain the “statistical comparability” (Oakley, 1981, p. 30). The notion of gender influences the interviewing process as it has been shaped by traditional paradigms (Devault, 1999). Therefore, issues of power and privilege arise in the interview process-- especially when performing the interviewing process as women who articulate our experiences into standard vocabulary (Devault, 1990). Devault (1990) suggests that we must go beyond standard vocabulary to fully describe women’s experiences in not just our analyses, but also our methods in interviewing. Ultimately, the traditional interview style is a structured approach, which is not necessarily problematic by itself, but there are risks of reinforcing power differentials if the interviewer does not consider the interviewee’s point of view.

### **Feminist Research Methodology**

Despite these limitations to traditional interviewing, interviewing can be appealing to feminist researchers because it provides an opportunity for participants to share their lived experiences and knowledge. Feminist scholars have critiqued and re-

appropriated interviewing to serve feminist scholarly research best practices. According to Reinharz (1992), central themes to feminist research methods include viewing feminism as a perspective rather than a method, using multiple methodological approaches, critiques of non-feminist research, guidance by feminist theories, taking an interactive approach to research, involving the readers as a person, and striving for human diversity. For my study, I adopt Reinharz's (1992) best practices of feminist research as a guide to my own research. For example, I take an interactive approach to interviewing and use feminist theories and multiple methodological approaches to guide my study. Additionally, I center the participants' experiences and reflect on power differentials amongst participants and the researcher.

**Interactive interviewing.** In contrast to the traditional approach to interviewing, the ambitions of interactive interviewing align closely with the best practices of feminist research. Interactive interviewing stipulates an opportunity for “an in-depth and intimate understanding” of people's lived experiences (Ellis, Kiesinger, Tillman-Healy, 1997, p. 121). For example, interactive interviewing allows for a semi-structured, collaborative interview that examines people's experiences rather than producing standardized information (Ellis et al., 1997). Interactive interviewing also avoids centering and thus hierarchizing the interviewer (Ellis et al, 1997). Ultimately, this interviewing approach creates a conversation that prompts the sharing of stories from both the researcher and the participant, which, oftentimes, develops a connectedness between the two (Ellis et al; Reinharz, 1992).

**Autoethnography.** Interactive interviewing can be useful for feminist researchers when the decision to self-disclose is present and is a useful tool to potentially alter the researcher's role (Ellis et al; Reinharz, 1992). In my study, I disclose

my condition and baldness to participants by using an interactive approach to interviewing, which in my case adds an autoethnographic element to the study.

Autoethnographic research combines the personal experiences of the researcher with the cultural context of those experiences (Ellis, 2004). As a woman with monilethrix, my own prior knowledge and experiences are present throughout the research, interviewing and writing process.

**Interpretive phenomenological analysis.** Because interviewing solicits women to share their narratives of baldness, interpretive phenomenological analysis assists in extracting common themes that emerge in the interviews. Phenomenological research examines the meanings of human experience and attempts to understand the ways that consciousness, language, and context shape these meanings (Adams & van Manen, 2008; Creswell, 2007). Phenomenology has roots in philosophy but has recently adopted a broader meaning within humanities and social sciences because it offers an alternative to analytical, managerial, and technological ways of knowledge (Adams & van Manen, 2008). Feminist scholars critique the privileging of scientific inquiry because qualitative methods such as phenomenology are particularly appealing to feminist scholars. Although there is no formal way of practicing phenomenology, it often is through an empirical or a reflective approach (Adams & van Manen, 2008; Creswell, 2007). My study focuses on the reflective approach to phenomenological analysis, which is also known as an interpretive approach.

Interpretive phenomenological research contends that the human is “embodied, situated, finite, and thrown into a particular culture, time, and place” (Benner, 2008, p. 462). Interpretive phenomenology challenges universal assumptions of the self and the mind-body dualism and views the individual as a socially constituted and situated

participant in language (Benner, 2008). Interpretive phenomenology unpacks unnoticed assumptions and challenges existing ones. Therefore, as the researcher, it is imperative to reflect on my own assumptions throughout the research and writing process, especially when conducting interviews and analyzing participants' experiences. Interpretive phenomenological analysis does not aim to make generalizations or causal explanations but instead attempts to discover commonalities and explicate taken-for-granted assumptions. When practicing interpretive phenomenology, there are three strategies to discovering and organizing findings (Benner, 2008). For my study, I use thematic analysis, which reflects and organizes patterns, concerns, and commonalities of the participants. By using interpretive phenomenological thematic analysis, I aim to understand and share common experiences of female baldness through the voices of women who are bald from skin and hair disorders. Recognizing that experiences of baldness are not universal, I acknowledge and discuss some differences.

**Interactive interviewing, phenomenological analysis, and my study.** I apply a qualitative exploratory approach by using interactive, semi-structured interviews to gather information. Given that the main purpose of this study is to share women's experiences of baldness from skin and hair disorders, interactive interviewing is a suitable method for providing an opportunity for participants to voice and share their experiences in their own words. Additional goals include situating participants' experiences into historical context and considering how participants accommodate and resist notions of femininity depending on space and time; interpretive phenomenological analysis is a particularly useful method because it asserts that the individual is a socially constituted participant in language and discourse. When doing

interpretive phenomenological analysis, context affects discourse and helps examine underlying taken-for-granted assumptions.

For my study, I interviewed four women who experience baldness from alopecia areata, alopecia totalis, alopecia universalis, and monilethrix. The sample size is feasible for the study because interpretive phenomenological analysis does not aim to generalize research but to extract commonalities amongst participants' experiences. Additionally, the sample size is conducive with thesis project time constraints. Interviews were conducted using the online videoconferencing services Skype and FaceTime. The audio program Audio Hijack Pro was used to record interviews, and these recordings were transcribed verbatim for later thematic analysis. While transcribing, I used pseudonyms to protect participants' identities and to meet IRB confidentiality standards.

***Participant selection.*** With the exception of one, participants were recruited using the social networking site Instagram and its “hashtag” system; a hashtag represented by the “#” symbol and “tags,” or marks, keywords, phrases and topics created by users (Twitter Inc., 2014). Twitter, another social networking site, originally created the hashtag as a way to organize and categorize messages, and other social network sites like, Facebook and Instagram have since adopted it. By using common alopecia and baldness awareness communication hashtags like, #rockyourbald, #mybaldisbeautiful, #365daysofbald, #baldbeauties, #alopeciaawareness, #nohairdontcare, and #balddiaries, I identified potential participants. Some of the hashtags are not distinct to women or baldness from skin and hair disorders; however, on the call-for-participants Instagram post, I was detailed in my description of prospective participants. Requirements for participants included: women; over the age of 18; experience baldness from alopecia areata, alopecia totalis, alopecia universalis, or

monilethrix; voluntary participation; and ability to provide written proof of informed consent. Skin and hair conditions affect people from all geographic locations and backgrounds, and for those reasons, it was important to strategize the recruiting process to be widespread in the dissemination of information to prospective participants.

On the one hand, marginalized communities continue to use the constantly growing Internet for organizing and public awareness (McKenna & Bargh, 1998). For instance, the National Alopecia Areata Foundation uses the Internet to reach out, organize, and provide spaces of support for people with baldness from alopecia areata conditions (Kalabokes & Besta, 2001). On the other hand, by using the Internet and specifically Instagram as the recruiting tool for participants, I am potentially soliciting a particularly active person within this community. However, it is reductive to assume that Instagram does not reach out to a varied group of people within the alopecia and baldness community and that these people's levels of activeness does not range. To illustrate, I implement McKenna and Bargh's (1998) distinction between "posters" and "lurkers." A poster is someone who provides reading material for others; whereas, lurkers read the material posted by others. Unlike McKenna and Bargh (1998), it is outside the scope and purpose of this study to understand the participants' level of activity within these sites. Nevertheless, underlying the recruiting process of participants this conversation on posters and lurkers is relevant. Prior to my research, I was an active member on Instagram who browsed hashtags that were specific to baldness awareness campaigns. Although I was browsing the hashtags and engaging in what others' post, I was not posting or sharing information with others. In this respect, I would be considered a lurker, which does entail some level of activity, but not necessarily as much as a poster. In sum, I do recognize the potential limitation of

recruiting a certain active participant within the recruiting process, but I remain reflective of this throughout the research and writing process. In the following sections, I provide the demographics and descriptions of participants along with the potential risks and benefits associated with participation in this study.

***Sample of participants.*** The recruitment process resulted in four women who live in the United States, ranged in age from 23 to 31 years old, and three of the four participants identify as white and one participant identifies as Mexican-American. Significantly, the age of onset of baldness and/or the condition varied amongst participants and demonstrates differences in their experiences of hair loss and/or baldness. In the following, I briefly describe details of each participants' conditions and lives that are relevant to my study.

The first participant I interviewed was Emily. Emily is a 23-year-old Mexican-American woman from Nevada. She experiences complete loss of head hair and eyebrows and partial loss of eyelashes. In the interview, Emily stated that she wanted to participate in my study because she desires to become more comfortable talking openly about her baldness and her condition. Emily began experiencing alopecia areata and hair loss at the age of 13. During this initial time, Emily was able to manage her condition by covering her bald spots with existing hair or by wearing hats. However, around the age of 14, Emily began experiencing regrowth in head hair. Accordingly, she was not necessarily shocked that she experienced regrowth, but she explained that she was just a young girl who wanted to live life at the time and did not think she would eventually lose all of her hair. Then, at the age of 15, while Emily was on winter break from school she began rapidly losing her hair again. Emily returned to school bald, but she wore a wig to cover her baldness; however, she explained that the other students

still were aware that she was “different.” When Emily returned to school from break, she only stayed until lunchtime and never returned to public high school because of girl-hate and bullying, which will be expanded on in the discussion section. Today, Emily manages her condition with a turban, but reveals that she has never exposed her bald in public.

The second participant I interviewed was Janet. Janet is a 25-year-old woman from Ohio and experiences baldness from monilethrix. Janet experienced the onset of monilethrix at infancy, and there was a family history of the condition. However, according to the interview, Janet’s knowledge on the condition is still minimal to this day. Janet’s paternal side of the family experience monilethrix, so growing up her knowledge was learned from her paternal grandmother. Janet explained that her mother and father attempted to help her when she was a child, but her mother had limited knowledge on the condition and her father wore his bald because that was more socially acceptable for men. Therefore, due to generational differences, Janet’s grandmother was secretive about the condition and baldness. In the interview, Janet attributes the way her grandmother coped with the condition and her own lack of knowledge on monilethrix to her general fears, hesitations, and anxieties, which she believes are the result of her experiences with monilethrix and baldness. Furthermore, Janet stated that she manages her condition by wearing a synthetic wig everyday. Ever since childhood, Janet has managed her condition by wearing a wig, which happens to be the same way her grandmother manages her condition. Similar to Emily, Janet reveals that she has never worn her bald in public on purpose. Additionally, Janet was the participant that was recruited through a previous interaction we had together, rather

than through Instagram. Monilethrix is a rare condition and this may explain why no one with monilethrix responded through the call-for-participants on Instagram.

The third participant I interviewed was Penny. Penny is a 29 year-old-woman from Connecticut. Penny experiences alopecia areata with the onset of her condition at 24 years of age. Throughout the interview, Penny discussed several ways of managing her condition. For instance, in the beginning, Penny stated that she would use existing hair to cover up bald spots. However, Penny also explained that she eventually came to a point of “f it” and she decided to shave her head; this initial experience of shaving her head will be further examined in the discussion chapter. While Penny continued to shave her head over the course of four years, she managed her condition by wearing a scarf in public. In the interview, Penny described that as her life changes so does her relationship her hair, baldness, or management style. Therefore, Penny explained that she no longer shaves her head and this allows for her hair to regrow (or not).

Additionally, Penny stated that her eyebrows have become extremely vague since the onset of her condition. For Penny, this concern around her eyebrows is an additional anxiety and management technique that she has learned as a result of her baldness. In particular, Penny described that she never was too concerned about the maintenance of her eyebrows until the onset of her condition, and so Penny’s baldness produces her attachment to her specific type of eyebrow liner. In addition to autoimmune alopecia areata conditions, Penny experiences Hashimoto’s thyroiditis, which was diagnosed around the time of her alopecia areata. Hashimoto’s thyroiditis is an autoimmune, underactive thyroid condition. Although Penny experiences a condition in addition to her alopecia areata, Penny does not necessarily identify as ill. Despite her rejection of

illness, some people still associate her baldness with illness, which will be examined in the discussion chapter.

The final participant I interviewed was Ashley. Ashley is a 31-year-old woman and mother of two children. Similar to Penny, Ashley is from Connecticut and experiences alopecia areata. Ashley's onset of alopecia areata was at 29 and a half years of age; simultaneously during this time Ashley was planning her wedding. Throughout Ashley's interview, she often reflected on how the onset of her baldness and condition was a challenge when navigating her several roles. Furthermore, Ashley discussed how her several roles influence her management strategy in certain contexts. Comparable to Emily and Penny, Ashley began managing her condition by covering up bald spots with hair. Like Penny, Ashley disclosed that she came to a point where she was exhausted with worrying about her bald spots, so she shaved her head. After shaving her head, Ashley allowed her hair to grow back (or not) and, because of regrowth and relapse of hair, Ashley currently manages her condition by wearing it in a mohawk. However, Ashley's experiences reveal that even this hairstyle poses challenges for her in certain contexts, especially the workplace. I unpack these themes of context and management techniques more in the discussion chapter.

***Risks, benefits, and confidentiality.*** Talking about personal experiences has the potential to evoke feelings of discomfort or distress for participants, but there are no risks associated with interactive interviewing. In other words, based on IRB standards, I consider my study to be minimal risk. The participants signed and submitted an IRB-approved informed consent form. Additionally, at the beginning of each interview, I reviewed the informed consent form with participants and offered the choice to stop the interviewing, recording, or participating in the research at any time

during the process. As noted, pseudonyms were used throughout the transcription and writing process to maintain confidentiality.

Although there are no guaranteed, direct benefits associated with this study, participants may gain indirect benefits by participating in my research. As aforementioned, by using Instagram hashtags to recruit participants, I am potentially reaching out to women who are more active in this community of baldness and who embrace the visibility of alopecia and baldness awareness. Accordingly, it is possible that contributing to this community and sharing stories about their experiences of baldness can benefit the participants.

***Thematic analysis.*** Based on my analysis of four women's lived experiences with baldness from alopecia areata, alopecia totalis, alopecia universalis, and monilethrix, I include two overarching themes, which include (a) navigating the feminine ideal and (b) negotiating the assumptions of illness and female baldness. In the following chapter, I explain and analyze these two themes.

## **Chapter Four: Discussion**

### **Complexities of Accommodating and Resisting Hegemonic Notions**

I adopted the notions of accommodation and resistance from Weitz's (2001) article titled "Women and Their Hair: Seeking Power Through Resistance and Accommodation," which examined how women seek power through accommodation and resistance in everyday activities. Even though I follow Weitz and consider how women who are bald from skin and hair conditions seek power through accommodation and resistance, participants' experiences reveal that organizing themes of accommodation and resistance into a binary is problematic and limiting. Interpreting experiences within a binary can potentially reify the erasure of context and may lead to presumptions about participants in my analysis. Instead, I will show how participants' experiences are more complex and fluid between accommodation and resistance in relation to hegemonic notions that prevail around femininity, illness, and female baldness. Women's accommodation and resistance are never really static, and are continuously shaped through institutional discourses, societal expectations, and interpersonal interactions.

In this chapter, I divide participants' experiences into two themes, which include (a) navigating ideal femininity and (b) negotiating the assumptions of illness and female baldness. In the first theme, I provide examples of management techniques ranging from hiding bald spots; wearing turbans, wigs, and bandanas; shaving the head; rocking one's bald; and management of eyebrows and eyelashes. Through navigating the

feminine ideal, participants become experts on their condition and gain more control and knowledge over their baldness, which contribute to their becoming more self-accepting despite dominant standards. Interestingly, participants' experiences expose practical reasons and implications for accommodating and/or resisting the expectations of the feminine ideal within a Western, patriarchal, capitalistic, heterosexist society. Throughout the second theme, I analyze assumptions of illness around female baldness, such as cancer, and ultimately projected onto participants. In some contexts, participants interact with the medical institution in hopes of answers, knowledge, and support; however, participants simultaneously reject narratives and identities of illness. In both of these themes, I consider how hegemonic discourses surrounding the historical expectations of what a female body is supposed to look like constitutes participants' shared experiences. Shared experiences include coming out about their condition and baldness, having anxieties in certain contexts, internalizing societal expectations, experiencing depression, acts of resistance, and self-acceptance.

### **Navigating the Feminine Ideal**

Because of the historical and cultural significance that hair has in relation to femininity, participants' interviews suggest that accommodation and resistance of hegemonic ideals of femininity are contextual and do not always reflect participants' intent or decision. The historical context and dominant discourses of femininity constitute participants' performances of femininity, which ultimately limit participants' experiences and influence their choices within these experiences (Scott, 1993). As Butler (1990) reminds us, there are punitive consequences if participants fail to perform femininity correctly in certain situations. Therefore, it is significant to consider how these consequences potentially complicate participants' accommodation and/or

resistance of the expectations of the feminine ideal. In this section, I examine how participants accommodate and resist hegemonic ideals of femininity. To achieve this, I organize this theme into the following sub-themes: management techniques that participants use and the contexts in which they use them; challenging experiences, such as navigating people's expectations, feelings and experiences of depression, and memories of bullying; and finding a way to live happily as a woman with baldness from a skin or hair condition through redefining standards of beauty and femininity for their lives.

**Management of baldness.** Due to the general lack of knowledge on various management techniques and the discourses of femininity that influence certain management techniques over others, participants experience their conditions and baldness within a historical and cultural context and this limits their choices of management techniques. Participants' descriptions behind their management techniques reveal that there are personal, practical, and contextual reasons for their strategy, rather than merely accommodating and/or resisting the performance of the feminine ideal. To briefly review participants' current management techniques, Emily currently wears a turban. Additionally, Emily has never exposed her bald in public. Because Emily has alopecia universalis, she also manages her condition by drawing on her eyebrows. The second participant, Janet, manages her baldness by wearing a wig ever since childhood. Similar to Emily, Janet has never intentionally revealed her bald in public. The third participant Penny manages her alopecia areata by covering patches of bald spots with existing hair and by darkening her eyebrows with liner. In our interview, Penny shares experiences that disclose she used to shave her head and that she wore scarves. The final participant, Ashley, also experiences the cyclical pattern of

alopecia areata. Therefore, regrowth and relapse allows Ashley to currently wear her hair in a mohawk. Similar to Penny, Ashley shares prior experiences of shaving her head, but also shares experiences of owning a wig and hiding bald spots by covering patches with existing hair. As participants' experiences demonstrate, there are several ways to customize the management of one's baldness and condition. However, the current literature disproportionately reflects the management of female baldness through wigs. Pairing this literature with the hypervisibility of scarves and chemotherapy-induced female baldness, the representation of management techniques surrounding female baldness is minimal at best. In a society compelled by a true gender identity, there are historical and cultural expectations of how female bodies are supposed to appear in this society. I consider how participants' decisions and experiences of management techniques have the potential to simultaneously reify and challenge hegemonic notions of femininity. For instance, one of the experiences that participants share surrounding navigating the expectations of female bodies and management techniques is a general anxiety and fear of exposure.

***Being exposed.*** Despite the different ways participants manage their baldness and condition, participants share similar anxieties and fears of exposure. For instance, Janet explains these fears and negative experiences are prevalent in her childhood and adolescent memories of her wig and baldness. In our interview, Janet shares that she feels her condition causes her not to be as “outgoing and daring.” Emulating this point, Janet stated, “I love roller coasters, terrified to ride them ‘cause I’m afraid of my hair. Same with canoeing, like I love canoeing, but I’m afraid something’s—you know, like I’m always afraid that something’s gonna happen, like, it falls off.” Similar to Janet’s interview, the discussion of rollercoasters also appears in my

interview with Emily, even though Emily manages her condition differently than Janet. Emily conveyed similar anxieties about exposure when she described an upcoming, surprise trip to Universal Studios in California with her boyfriend when she stated:

The day he told me [about the trip] I got sick to my stomach, and I was like the whole day, I threw up. I made myself throw up because it's just I get anxiety, you know, just the fact that...how am I gonna tell him that the reason I don't wanna go is for that reason?

Emily's fear of her turban falling off during a ride reveals a common problem for women who manage their baldness. As Janet infers these fears do not go unsolicited because prior experiences validate her anxieties. At one point in our interview, Janet stated: "every time I go to the ocean, I lose my wig." In hindsight, Janet finds humor in this story, but she expresses a serious fear and anxiety around exposure in situations where she may lose her wig.

Similarly, Emily described how a prior experience confirms her fears of exposure when she reflected on her first experience at the DMV and she had to take her picture after the onset of her condition. Emily explained that "the guy [at the DMV], he was like 'I need to see your hairline' and I was like 'I don't have one,' and he was like, 'but I need to see it anyways,' and I'm just like 'how am I going to show you if I don't have one?'" According to Emily, the DMV was busy at the time and the man working almost made her take off her turban. For Emily, this experience was extremely uncomfortable and she "just wanted to run out of there." Emily's and Janet's anxieties of exposure can be attributed to expectations of the feminine ideal, but, as their experiences demonstrated, these anxieties and fears also position participants in situations where they are forced or coerced to "come out" with their baldness or condition. Furthermore, Emily and Janet's fear of exposure reflect Bartky's (1990) discussion of women's internalized self-

surveillance and constant maintenance of the particular, feminine bodily practices that the dominant discourse assumes for female bodies. In sum, participants are aware that baldness on female bodies is different than societal expectations of women and their fear of exposure reflects these internalized beliefs.

Penny seems to share this anxiety that Janet and Emily voice, even though they all three manage their baldness differently. Penny wore a scarf for four years to manage her baldness, but because of regrowth she now manages her bald spots by covering them with existing hair. When I asked Penny what was particularly challenging about her condition, Penny responded, “I worry a lot if my bald spots are going to show...um, I—there are times that I will, like, I’ll touch the back of my head to make sure it’s covered.” Penny’s constant maintenance of her body mirrors the disciplinary practices created through the requirements of the hegemonic ideals of femininity. In other words, Penny, like Emily and Janet, is aware of the standards of femininity and internalizes this discourse, but if she does not, then, someone else may police her appearance by holding her accountable to accepted performances of femininity, regardless of her desires.

Due to the magnitude of their condition, Penny and Emily also manage their autoimmune alopecia areata conditions by using strategies that focus on the maintenance of their eyebrows and eyelashes. Emily mentioned this is an additional layer of anxiety when she explained that “it’s always like having to worry about if they came off or not, or ‘oh, I’m sweaty—let me make sure they’re still on.’” Emily is able to find humor in these experiences as she laughs throughout the interview, but Emily lives in Las Vegas, Nevada, so the geographical location and weather does matter in the management of her condition and contributes to participant’s accommodation and/or internalization of disciplinary practices of hegemonic ideals and constant maintenance

of female bodies. In a similar example, Penny shared that she “can get really bad anxiety about [her] eyebrows, like, if it rains.” Comparable to Emily, Penny fears that practical reasons and weather conditions may affect her management technique. Furthermore, Penny states it also is a challenge to make her eyebrows appear the same, and this challenge also contributes to her fears surrounding her eyebrows. Penny voiced that some days frustrate her because:

It’s like an art form to put eyebrows on cause like there will be some days where I have to dis—remove myself from the situation cause I just, um, like I have it pretty much figured out down to a science, but every once and a while I will have a day that they are so different looking from each other and it’s like hideous.

While eyebrow maintenance is a prevalent requirement in the contemporary discourses of femininity, Penny’s experience with her eyebrows require different maintenance and creates her attachment to her eyebrow liner. Due to a couple of situations where Penny’s eyebrow liner was not accessible, she finds herself constantly checking to guarantee that she has eyebrow liner in her purse. Ultimately, the loss of eyebrows exacerbates the severity and prevalence of Emily and Penny’s constant maintenance of their bodies, but also contribute to their accommodation and/or resistance of the feminine ideal.

Emily, Janet, and Penny’s experiences demonstrate the anxieties of exposure around participants’ management techniques, and reveals the internalization of hegemonic notions of femininity. However, these experiences go beyond the internalization of these standards of femininity because participants describe stories that validate their fears of exposure through societal rewards and punishments. These rewards and punishments contribute to participants’ need to navigate the feminine ideal and possibly dictates their management strategy in certain contexts. Furthermore, these rewards and punishments may contribute to participants’ accommodation and/or

resistance of hegemonic notions of beauty and femininity. Importantly, Ashley did not share experiences that suggested a fear or anxiety of exposure and may be in part because she manages her baldness in a mohawk or because she did not want to share this information at the time. Exacerbating participants' prevalence of anxieties around their baldness, participants seem to be unable to escape other people's assumptions of their performances of femininity in contexts, such as the workplace and through daily interactions with people. In the following section, I provide examples that describe how participants' daily interactions with strangers, acquaintances, and family members also contribute to their navigation of the feminine ideal. Additionally, I include experiences that demonstrate how workplace requirements of professionalism and the feminine ideal limit participants' management techniques.

***“It doesn’t matter what other people think, but it does.”*** In the interviews, participants are cognizant of cultural messages that assume other people's opinions do not matter; however, participants' lived experiences with female baldness from a skin and hair condition and their understandings of these experiences suggest that sometimes it does matter. It is easy to minimize the severity of an appearance-altering condition, such as autoimmune alopecia areata conditions and monilethrix, if one has not subjectively experienced a similar condition. While participants do have moments of carelessness, all participants exemplify how other people's opinions and interactions contribute to their navigation of the feminine ideal.

For illustration, I asked Janet why she wears a wig, and she initially responded that she feels “more attractive” with it. In an afterthought, Janet stated:

I-I am afraid of what someone could potentially say, I guess. I do care kind of about what people think about me and I think that, um, that would just be like

alarming and shocking to too many people and I'm not really like confrontational.

Suggestively, Janet acknowledges that baldness on female bodies may be shocking or unusual to some people. Therefore, Janet conceals her baldness by wearing a wig because she does care what people think about her and their presumptions about her baldness. In other words, societal expectations of female bodies constitute Janet's fear of exposure and confrontation surrounding her baldness and, perhaps, influences her management techniques. In addition the feminine ideal, Janet's experiences with maintaining societal expectations of female bodies with a condition such as monilethrix also reveal the classist assumptions underlying the feminine ideal.

Intersecting systems of oppressions reproduce contemporary expectations and disciplinary practices of hegemonic ideals of femininity. For instance, Janet was raised in a working class family, and financial burdens magnify the complexities of Janet's maintaining standards of femininity because her multiple subjectivities limit her "choices." With frustration, Janet exclaimed:

That's another thing, like—I think that has always pissed me off about [this condition] is they don't really make it easy. Like, if you don't have money you're not—like if you had money, if I was rich, I'd be able to buy a new wig every week...human hair, and I'd be looking, you know, it would always look like it was real.

Janet purchases synthetic wigs because they are less expensive than human hair wigs. This price difference frustrates Janet because if worn everyday her hair looks "fake," or "crispy" after time as she described it. The fact that Janet does not want her hair to appear "fake," even though it is a synthetically manufactured wig, is extremely telling. For Janet, the quality of her wig potentially exposes her condition or represents an imperfection in a society that demands perfection. Throughout her experience, Janet

has learned to manage her synthetic wigs, such as wearing them in a low bun or side braid to hide the prevalence of the “crispiness” at the ends of the wig. Now that Janet is older and independent, she knows to buy a new wig about once a month, but even this is still a struggle. As aforementioned, Janet was raised in a working class family, and her interview reveals the financial challenge her parents faced when trying to buy a wig often enough to where it did not appear “fake.” Reflecting this point, Janet disclosed:

I look at pictures and I’m so humiliated of how my hair looks in some pictures when I was little that I feel like, now, I’m less likely to be upset about my hair because I can control it. I know when to get a new one, I know when it’s gonna look real I know when—you know? Like, I feel like you try to adapt to that, and I don’t think [my] mom necessarily understood because one, they were broke and they couldn’t afford a new one every month.

Janet’s performance of femininity relies on the quality and texture of her wig. However, the quality and texture of her wig also depends on her ability to afford a new one about once a month. In other words, Janet’s multiple subjectivities also influence her accommodation and/or resistance to the feminine ideal.

In addition to other people’s opinions of their baldness, participants’ experiences show that institutional standards also dictate their performance of femininity. Specifically, participants’ experiences imply that the workplace is an area that influences their choice of management strategy in certain context in order to adhere to regulations and expectations. For example, Ashley disclosed that she works with elderly people and through her prior experiences at work, she knows it is easier to manage her baldness with a scarf because “they’re not really accepting of a female with a mohawk.” Ashley recognizes that generational differences contribute to her patient’s expectations of her appearance when she stated “it was way different back then [sic],”—referring to a

general time when her patients were raised; and therefore, Ashley alters her management preference to ward off other people's expectations of female bodies.

Emily has a similar experience in the workplace setting, but does not necessarily relate it to generational understandings of female bodies. Instead, Emily describes a culture of business that uses women's bodies to represent and market the company. Emily currently works at Home Depot, but she believes that there is more money in Las Vegas as a cocktail server. Regardless of the financial motivation, Emily fears applying for jobs that are similar to cocktail server positions because these positions rely on dominant standards of beauty and attractiveness. Mirroring this point, Emily explained:

I've been going to the gym a lot and I've been trying to workout to get myself in good shape, um, because I wanna—I wanna try for like cocktail waitressing. And the more that I think about it, the more I wanna tell myself not to do it and being bald is the reason I don't wanna do it because I know the minute that I walk into the interview I'm gonna be different from all the girls, you know?

Emily feels that she is unable to go into an interview and “be bald and fat.” Although she was laughing when she said this, Emily admitted her reason for exercising has been, “so they only have one thing against me.” Emily acknowledges that the effects of alopecia universalis are outside the expectations of hegemonic ideals of femininity, but she also recognizes that in certain contexts she must maintain bodily expectations of the ideal femininity. Therefore, in certain contexts that enforce societal expectations of female bodies, participants must accommodate hegemonic notions of the feminine ideal due to societal rewards and/or punishments. However, participants' interviews also expose that they are not cultural dupes; and therefore, there are situations where they demonstrate acts of resistance through their management choices.

**“I was just like fit and I just shaved my head.”** Although other people's projections of societal expectations impact participants' management choices,

participants still find ways to resist and express themselves through management strategies. In the interviews with participants, there were times of explicit resistance to hegemonic notions and this resistance clearly influenced their management decision. For example, Penny and Ashley shared instances of expressing resistance and control over their conditions and bodies through shaving their heads.

As previously mentioned, Penny and Ashley's experiences with alopecia areata involved more sporadic regrowth and relapse. According to both of their interviews, this rapid regrowth and relapse was an emotional challenge and additional anxiety. For instance, Penny explained that she came to the point of "f it" and shaved her head because she was in tears every time she showered due to it falling out. However, Penny acknowledged that other life events played a role in deciding her to shave her head, too. For example, at this time, Penny experienced extreme weight loss and gain because in addition to alopecia areata she was diagnosed with Hashimoto's thyroiditis, which is an underactive thyroid condition. Additionally, Penny was in her mid-twenties and commonly experienced feelings of unattractiveness over these changes with her body and hair. Reflecting on these life stresses, Penny stated "[I'm] in my mid-twenties and all these things kept coming up like...It's just like not feeling attractive, like, I was always feeling like everyone was always looking at me." Therefore, once Penny decided to shave her head, she explained that the experience of shaving her head for the first time was "totally liberating," "so cool," and even explained that her closest friends had a ceremonial initiation and welcomed her baldness. In the interview, Penny described that her life was more positive at this time and she was happy with her decision because she found a way to take control over her body and condition. However, Penny also stated "the novelty of it wore off really quick." Once Penny shaved her head for the first

time, she continued to shave her head about four times over the course of four years. During this time, Penny wore scarves in public, and there is a prevalent cultural representation of the scarf with cancer. I discuss this association of female baldness with cancer in the following theme, but for now I want to demonstrate that, as a result of this representation of scarves to cancer, Penny often found herself in situations where she had to explain her baldness, condition, and reason for scarves. After four years, Penny was tired of these interactions and explanations. Simultaneously, Penny discussed that she experienced more life challenges at this time. At 25, Penny lost her mother, she experienced a “shitty break up,” and other life stresses changed her relationship with her hair. Penny expressed “it was just kind of like my hair became this thing where I was just, like, I was so sick of the scarves.” Penny’s changing relationship with her baldness, hair, and management styles reflects Weitz’s (2004) contention that women oftentimes express personal changes through their hair. Even though Penny does not grow hair, she still finds ways to express herself through her management techniques and baldness.

Through Penny’s shaved head and scarves, she challenged hegemonic notions of femininity, but these experiences unpack the complexities behind accommodating and resisting hegemonic notions of beauty and femininity. While Penny shaved her head and managed her baldness with scarves, she still could not control presumptions around her baldness or management technique. Once again, Penny was exhausted with the lack of control over her body and life at this time. Penny enjoyed her shaved head for quite some time, but as she described the novelty wore off and her acts of resistance to beauty norms and her conditions were contextual and short-lived. Penny explains that, sometimes, there is still an urge to shave her head again, but for now, she allows her hair to grow (or not) based on the unpredictable pattern of her condition. Penny’s

experiences with shaving her head magnify the complexities of navigating the feminine ideal. Due to the rewards and burdens attached with appropriately or inappropriately performing femininity, it may be easier and/or more rewarding for participants to accommodate the ideal in some contexts.

Likewise, Ashley came to a decision to shave her head while experiencing the cyclical pattern of alopecia areata. Prior to shaving her head and similar to Penny, Ashley explained that she faced several stressful life changes. As Ashley described this time during her life, “it was a lot.” To illustrate, Ashley described the first time she shaved her head as follows:

So, last year, in the beginning of May, we were doing--I was volunteering for this kid's cancer fundraiser and the barber, who's my husband's barber, he's the one that was doing it and he was talking about my hair. He's like let's just shave your head. We were in his shop for the meeting with the fundraising and...I only had but this tiny, tiny bit left on my head, so I was just like-- let's just do it. So, he made a big old video tape, you know, about it—that there are so many people around that you just don't know of who like have cancer, or have alopecia, or whatever it is, that are struggling to deal with things themselves. So it was-- it was nice and it was like an outlet for me to get out and be more open and be more accepting towards myself knowing, you know, that other people know. Not for me to go around and just be like, oh, I have alopecia.

After Ashley shaved her head, she felt relieved because she was “just getting it [her condition] out there.” Ashley's act of shaving her head paired with the video allowed her to “come out” to individuals who may have not been aware of her condition or hair loss, but also to help her resist hegemonic expectations of femininity. Prior to her shaved head, Ashley did not feel socially acceptable, so, for her and her family, Ashley's shaved head represented her carelessness and her self-acceptance. Like Penny, Ashley explained that her shaved head and self-acceptance was coupled with positive life changes—including her condition. Specifically, Ashley noticed regrowth with her hair simultaneously when her life began to become less stressful. Once Ashley saw some

“peach fuzz,” she stopped shaving her head because, as she explained, it was about to be a Connecticut winter and she wanted to “just see what happens.” After Ashley stopped shaving her head, Ashley experienced more regrowth and relapse. Today, her current state of her condition allows Ashley to style her hair in a mohawk. Ashley’s mohawk still situates her outside of some people’s expectations of female bodies, but the process of shaving her head and finding control has helped her learn to accept herself as a woman.

Participants’ experiences of baldness from skin or hair conditions and their understandings of these experiences reveal how their management techniques may be dictated by societal expectations of female bodies, internalization, and through prior experiences with interpersonal interactions. Furthermore, participants’ management techniques are not necessarily indicative of accommodation and/or resistance to hegemonic notions without including context. Participants’ interviews unpack the practical, personal, and structural reasons behind their choice of management techniques. As the above suggests, participants’ management strategies vary, but still participants share similar experiences. For example, some participants’ demonstrate general fears and anxieties of exposure surrounding their baldness, which may contribute to their accommodation and/or resistance to hegemonic notions. Additionally, Ashley and Penny demonstrate their carelessness and control over their condition through shaving their head.

To paraphrase Scott (1993), historical context matters to the evidence of experience because it exposes how shared experiences constitute subjects. Therefore, participants’ shared experiences with baldness from skin and hair conditions position them in a historical context with limited experiences and choices. While participants’ interviews clearly demonstrate differences amongst their experiences and choices, the

interviews also suggest that these experiences of baldness contribute to the fact that all four participants encompass a general self-acceptance of their condition, baldness, and bodies today. In the following section, I provide excerpts of the shared experiences that, I believe, contribute to participants' self-acceptance. These shared experiences include feelings of depression, bullying, and low self-worth. In spite of these negative experiences, participants' interviews suggest that they have redefined standards of beauty through self-acceptance and, now, they desire to live unapologetically as women who are bald, which I also discuss in the following section.

**“I didn't know how to deal with it, so I was just depressed.”** At some point in the interview, all participants expressed experiences of depression and attributed most of these experiences to their baldness and condition. By way of illustration, Ashley, a mother of two, stated:

I didn't know how to deal with it, so I was just depressed, like that's just how it was. I didn't go anywhere...in the beginning, I was working 40 hours a week. I was still going to school. I had my two kids. My daughter wasn't in school, yet, she's in kindergarten, now, so I didn't wanna do anything. I didn't wanna be around anybody, I didn't feel socially acceptable at all.

Depression exacerbates loss of interest in activities and feelings of isolation as implied in Ashley's interview. Additionally, Ashley described this time was especially hard for her because she did not feel socially acceptable, but went on to explain that she was aware stress and depression can worsen hair loss. Because of feelings of depression and inadequacy, Ashley blamed her physical changes on herself by holding herself accountable for her hair loss. Expressing similar feelings of depression and loss of interest, Penny explained, “I made it my own struggle...it was like I was depressed because of it, and when you're upset or depressed about something you don't want to talk about it all the time or whatever.” In other words, Penny attempted to ignore her

condition and baldness because the feelings of depression inclined her to be more closed-off. Interestingly, Penny and Ashley experienced their onset of baldness at a later age in their life. When Penny and Ashley discuss their feelings of depression, they harken more to bodily changes and lack of control. However, Janet and Emily's onset was earlier in life, and their interviews demonstrate how feelings of depression may also be present due to effects of girlhood bullying and feeling excluded from adolescent events.

Due to the age of Janet and Emily's onset, these two participants share similar experiences throughout girlhood and adolescent years, such as experiencing girl hate, bullying, and finding alternative ways to seek male attention, which both associate to their feelings of depression, unattractiveness, and low self-worth. For example, Emily shared a story about one girl who bullied her to the point of dropping out of high school and exacerbated her feelings of depression surrounding her baldness. In the interview, Emily explained:

I still remember her name to this day and how she looked and everything, and she was probably the one—the main reason why I just didn't go back [to school] like she just kept asking me 'oh I know that's not your real hair, what happened to yours, oh that's the wrong type of wig for you.'

Emily recognizes that this girl's claims about her baldness were true, but she explained that she was still embarrassed and hurt by the way this girl condescendingly asked about it. As mentioned, Emily's condition rapidly returned while she was on winter break from school. Therefore, when Emily returned to school with a wig, it was obvious. Emily explained that this particular girl also disclosed Emily's baldness to other people at school until everybody was aware of the rumor on the day Emily returned from winter break. By lunchtime, Emily left school and never returned to public high school. After

Emily dropped out of high school, she did not find interest in anything and stated that she stayed in her room depressed for a year. Since dropping out of high school, Emily has received her GED and recently enrolled in a psychology program.

Comparably, Janet discussed that she experienced girl bullying in adolescent years. However, Janet stated that, for her, the bullying from boys was more devastating for her self-confidence when she avowed “the ones that stick to you are the guys--like, the guys that reject you and the guys that say hurtful things to you...cause you know, I mean like you said, ultimately, we want to be desirable.” Janet identifies as heterosexual, so for her experience she talks specifically about wanting to be desirable to cisgender men. Still, in the interview, Janet recognized that baldness may affect any one’s feelings of attractiveness and desirability despite their sexuality.

During their transition from girlhood to womanhood, Janet and Emily explain that they feel they overcompensated their unattractiveness for men’s attention by finding alternative ways, such as drinking and partying. To illustrate, Janet clarified:

I just know how I feel looking back on that like year and a half or two years that I was, you know, promiscuous and I just—I’m like, ‘why did I have so little self-worth?’ But I think all the compliments and the partying and like, you know, guys hitting on you when you’re—cause obviously when you’re drinking you have more confidence anyways. And, you know, like getting dressed up and just, you know, and, then, you end up sleeping with someone every night...I felt kinda lost and I felt that validated everything for me, like, I felt attractive because I was hooking up with all these dudes.

Janet was cautious not to shame or regret her decisions, but she explained that as she reflects on this time in her life she believes she overcompensated her baldness by being a “party girl.” Although depression and low self-esteem are not distinct to girls’ experiences of hair loss and baldness from skin and hair disorders, Janet associates her depression and low-self esteem to her baldness and condition. Specifically, Janet’s

internalized beliefs in the feminine ideal made her feel inadequate at a younger age in her life. However, Janet's lived experience with her baldness helps her to recognize that society has an unrealistic expectation of beauty for women; and therefore, she rejects these feelings of inadequacy through self-acceptance and rejecting media's expectations of beauty and femininity.

Despite the difference in age at onset, Penny and Ashley's had experiences of unattractiveness that are similar to Janet and Emily. At the time of her hair loss, Ashley was planning a wedding. Although her husband thought she was beautiful regardless, Ashley proclaimed, "it's still fresh and you're still a newlywed, and you know, you wanna be that hot wife." Ashley recognized that her condition impacted her soon-to-be husband, too, especially if she did not feel beautiful. Similar to Ashley, Penny described that she does not feel worthy for dating when she stated, "it's hard to have an intimacy when, um, when I'm like...when I'm not feeling worthy of it." In sum, the internalization of hegemonic ideals of femininity and beauty impacted Penny and Ashley's feelings of desirability and attractiveness.

As the above suggests, participants' interviews reveal shared experiences of depression, bullying, low self-worth, and unattractiveness. However, during the time of our interviews, participants seemed to have a general acceptance of their baldness. Through the rejection of internalized beliefs about hegemonic notions of femininity, participants learn to become more accepting of their baldness and condition. Participants' experiences with baldness position them outside the feminine ideal, but, due to the lived experiences that were constituted through this outsider position, participants' are extremely conscious of the dominant, unrealistic expectations within

the discourse of the feminine ideal. Following, I examine experiences where participants show acceptance of their baldness by taking control over their condition.

**“I see beauty in everything.”** Despite the prominent representation of the feminine ideal, participants find ways to accept their bodies and baldness through rejecting societal expectations of female bodies. Although participants continue to have frustrations, overall participants are genuinely happy and self-accepting. To illustrate, Janet clarified that “when I was younger, obviously, I thought it ruined my life, but I don’t think at this point in my life that it has taken away from my quality of life at all,” which is in contrast to existing medical literature that found people with alopecia have a lower quality of life (Cartwright et al., 2009). Through participants’ lived experiences of baldness from skin and hair disorders, participants learn to navigate their performance (and disruption) of femininity depending on context, needs, and desires. Participants reject the idea that their baldness is a threat or imperfection to their femininity despite the hegemonic ideal. Mirroring this, Penny shared “it kind of helped me let go of modern society’s idea of beauty.” Furthermore, participants wish this particular representation of femininity was not so prominent in the media and beauty industry. In this regard, Janet contended:

I think that, um, a lot of the negativity has a lot to do with like the media and how, then, little girls grow up thinking that things should be like that...I mean if people were more educated on things like this, then I feel like it would make it a lot easier for kids to deal with a condition like this.

Janet believes the media exposes young girls to narrow-minded representations of beauty. Accordingly, if there was a wider representation of women, girls, and beauty including representations of baldness, then, it would be easier for young girls, like Janet, to cope with their condition.

Participants have learned to embrace the notion that their performance of femininity is “different,” but for the participants that does not make them any less attractive, healthy, or woman. Emily has experienced alopecia areata conditions for a decade now, so she knows not to be excited if regrowth occurs because she has learned the cyclical pattern of the condition. However, it was learned that through lived experiences this regrowth is short-lived. Perhaps, this new knowledge helps control her anxieties about her condition. For example, Emily stated she recently experienced regrowth in her eyebrows, but she explained that she plucked these recent regrowth of hair out. When Emily shared this information with her boyfriend, he asked her why she plucked them. Initially, Emily responded with “I don’t know I’m just used to it.”

However, in hindsight, Emily specified:

I thought about the fact that, like, ‘why is it that I pluck my eyebrows when I-I’ve been waiting for so long for them to grow,’ and I think that it’s like I want to have control over my hair because I didn’t, you know? And that’s the reason why like... I just plucked them out, like, I feel like I want some kind of control whether they’re there or not because they got taken away from me.

While one could argue that the disciplinary practice of plucking eyebrows serves patriarchal functions (Bartky, 1990), instances similar to Emily’s eyebrow story illuminate the complexities of navigating the feminine ideal and, for Emily; this act is a form of control over her condition and express her self-acceptance.

Through this consciousness of self-acceptance, participants also collectively demonstrate a general acceptance for others who fall outside societal expectations of attractiveness and femininity. In Ashley’s interview, she declared, “maybe even being more open with not just myself, but everybody, and being able to talk about it because it is a hard thing to talk about—just like anything that you do go through.” In our interview, Ashley shared that she often engages in conversations with strangers about

her condition and these strangers' own stories. Although Ashley feels she was generally accepting before the onset of her alopecia areata, she explained that her condition and baldness has made her more cognizant about accepting others. Similarly, Penny pronounced:

I like see people and I'm just like I know who the real, beautiful people are...I mean I just—I love that about this that I'm able now like, and I think I've always been this way, I-I think I'm just more aware of it cause I just see the beauty in all people.

Again, Penny feels that she was accepting and open-minded prior to the onset of her alopecia areata, but she acknowledges that her condition and her hair loss has made her redefine beauty and made her more accepting of everyone. Although all participants demonstrate general self-acceptance and acceptance of others, they wish there were more reciprocation of this acceptance and awareness of them and their baldness. For example, Janet asserted that “this needs to be talked about and I feel like if people were more knowledgeable, then, you know, my situation would be different, um, I wouldn't have so many negative views on it.” By this, Janet suggests that navigating the feminine ideal would not necessarily be as noteworthy if society were overall more accepting.

While participants' lived experiences with baldness are ongoing, they demonstrate that with more time, knowledge, understanding, and support, participants potentially have the understanding to redefine control over their condition and baldness. In a society that privileges Western, white, abled-bodied ideals of femininity, the fact that participants learn to accept their bodies is monumental. I include moments that exemplify participants' level of happiness, acceptance of the self, and general approval of life because it is not necessarily transparent in existing literature. Although participants still have their days and moments of anxiety, fear, and frustration with their

baldness, participants come to the overall conclusion that “its just hair” and “it could be worse.” Participants are generally happy and want to enjoy life, and this is extremely apparent throughout the interviews. In a society that reduces women to a standardized, unrealistic female body, participants’ genuine self-acceptance is an act of resistance to hegemonic ideals of femininity in itself. In the following section, I examine the second theme, which considers how participants’ experiences with baldness from skin and hair conditions reveal participants also negotiate assumptions of illness and female baldness.

### **Negotiating the Assumptions of Illness and Female Baldness**

Female baldness is an antithesis to the feminine ideal; however, participants’ experiences suggest that female baldness is, oftentimes, culturally and historically symbolic of illness, cancer, and death. Western discourses around femininity and beauty assume that female bodies have hair. However, women with autoimmune alopecia areata conditions and monilethrix challenge these discourses through their conditions and their bodies. Interviews with participants demonstrate a general rejection of illness identities and narratives. Regardless of participants’ rejection, their conditions exist within a society that historically equates female baldness with illness. To begin this section, I define and explain medicalization in relation to alopecia areata, alopecia totalis, alopecia universalis, and monilethrix to understand and examine participants’ interactions with the medical industry despite their rejection of illness. Next, I discuss Emily and Penny’s experiences with cultural, familial, generational, and spiritual understandings of female baldness and illness. Then, I include an analysis on participants’ experiences that are specific to assumptions of cancer and chemotherapy-induced baldness. Ultimate, participants’ experiences with illness assumptions

demonstrate the complexities of rejecting illness in a society that defines, represents, treats and supports female baldness as an illness.

**Participants' interactions with the medical industry.** The term medicalization describes the process where nonmedical, human conditions become defined and treated as medical conditions (Conrad, 2007). While some baldness does warrant medical intervention, alopecia areata, alopecia totalis, alopecia universalis, and monilethrix are examples of human conditions that are nonmedical, but have been medicalized in this historical context based on socially constructed expectations of female bodies. For instance, the medical industry has defined these conditions, but continues to state that these conditions are asymptomatic and “medically benign” (Kalabokes & Best, 2001). In particular, alopecia areata is only thought to be an autoimmune condition because of its comorbidity with other autoimmune conditions; however, there are no conclusive studies on the autoimmune alopecia areata conditions (Messenger et al., 2012). This discussion of medicalization in relation to female baldness from skin and hair disorders is significant when considering future areas of research and medical advice surrounding these conditions. Currently, medical literature and research focuses on research that examines medical treatment; however, little is known about the causes of these conditions and effective treatment to these conditions is minimal. Rather than medical intervention, participants' experiences suggest the need and desire for psychosocial support, emotional resources, and knowledge on and access to various management techniques in order to cope and live with these conditions.

Even though the medical industry plays a role in the medicalization of female baldness, the medicalization of baldness is not one-sided. Specifically, women who experience hair loss or female baldness contribute to the medicalization of female

baldness due to their needs and/or desires constituted through societal expectations of the female body. Nevertheless, participants' interactions with the medical industry exist within a society that has already medicalized female baldness through historical, cultural, and spiritual understandings of female baldness as an illness. In other words, this medicalization produces and reproduces participants' interactions with the medical industry despite participants' rejection of illness. Even though the medical industry has defined participants' conditions, participants' experiences with baldness from skin and hair conditions suggest that the medical industry simultaneously undermines and invalidates participants' conditions and experiences of baldness by not providing adequate resources. Ultimately, participants negotiate a contested space and illness within a medical industry that has diagnosed them, but does not necessarily support their needs and desires. This paradox potentially complicates participants' experiences with baldness from skin and hair disorders. On the one hand, participants reject the idea that they are sick or ill. On the other hand, participants believe the medical industry could provide more support and resources and be more open to listening to their needs and/or desires surrounding their conditions.

By way of illustration, Emily, who has minimal eyelashes due to the effects of alopecia universalis, reflected on a conversation with her doctor about eyelash replacement when she stated "they were explaining to me 'Oh well it's just this cosmetic thing,' and I...I remember telling the...the doctor like 'okay, but it's emotional, you know?'" The doctor's comment to Emily about eyelash replacement being cosmetic reflects a healthcare insurance industry and fails to cover eyelash replacement as a medical intervention. For Emily, the loss of her eyelashes is the result of her alopecia areata and this loss has emotional consequences that are important to confront when

copied with her condition. Despite the lack of coverage for eyelash replacement, the insurance industry covers certain “medical” interventions, such as corticosteroids shots, which have limited effectiveness and a plethora of side effects. This difference in coverage infers that the insurance and medical industry view treatment for female baldness from skin and hair conditions as a medical concern that needs medical intervention, while arguing that eyelash replacement is cosmetic and ignoring patient’s desires. Consequently, the insurance and the medical industry are not fully considering the impact that ineffective medical treatment may have on women with baldness from autoimmune alopecia areata conditions and monilethrix. In our interview, Ashley exemplifies a potential impact of these medical treatments.

To begin, Ashley explained that the specialist in alopecia provided her with three options of medical treatment upon her initial visit. The first option of treatment suggested by the doctor was Rogaine, but it was ineffective and led to the second suggestion of corticosteroids shots. Ashley described frustration and agony with the shots when she stated “so, we did about 55 shots all the way through and it was the worst thing in my whole life. And I’m a tattoo person.” Ashley proclaimed that after six weeks she was supposed to return for the second set, but there had been no hair growth and, in fact, the hair loss had actually worsened. Although Ashley did not continue with the shots, she described this experience as “the worst thing in her whole life” and, admittedly, hoped for some effectiveness, but the opposite occurred and she experienced more hair loss. Once the shots were ineffective, the specialist suggested pills, which also had limited effectiveness. However, Ashley has other medical conditions and was concerned with the effects of medicine. Coupled with Ashley’s other medical conditions, the doctor revealed that the medication for the alopecia areata

would require her to take medicine to counter her other conditions and this would mean pills for the rest of her life. Once Ashley learned this information, she declined the pills. However, Ashley's interactions with the medical industry reflect the medical's institution reliance on the restitution narrative (Frank, 2006). The restitution narrative seeks and believes that there is a solution to the illness. In other words, the doctor, who is an agent of the medical industry, was concerned with finding a unidimensional answer to an untreatable condition and therefore not fully considering the effects that failed treatment had on Ashley. According to the interview, these effects included a sense of loss from invested time and money, depression, exhaustion, confusion, and a false sense of hope that she would see regrowth—even when she was aware the treatment has limited effectiveness. In other words, the medical industry was viewed as the expert and answer to Ashley's condition and baldness; however, alopecia areata is a chronic condition with no guaranteed treatment and it is important to provide this knowledge and reality to participants. As participants' experiences suggest, it is imperative for medical professionals to provide participants with a wide spectrum of medical intervention, management techniques, and nonmedical support in order to make coping with their condition and baldness an easier process. For example, Penny's interactions with the medical industry magnify the significance of providing participants with knowledge on their condition.

When Penny explained the onset of her condition and hair loss, Penny stated that once her hair started to fall out she researched on potential causes and after her research she decided to visit a dermatologist. However, Penny did not have insurance at the time, so it cost her 300 dollars for a visit. Accordingly, the dermatologist prescribed her “really really expensive medicine.” Although she cannot remember the name of the

medicine, she stated that it was topical, and the first night she used it she decided she was not going to use it anymore because it burned her scalp. In retrospect, Penny shared that she is startled that her dermatologist did not refer her to her primary doctor because as far as he initially told her she had an “inflamed scalp”— so her baldness was not necessarily diagnosed as alopecia areata at this initial visit with the dermatologist. After her visit, Penny still had questions about her baldness and whether it was the result of a medical condition, the environment, or if it was alopecia areata. As literature suggests, alopecia areata is understood to be “medically benign” other than hair loss. However, once Penny acquired insurance, she went to her primary doctor where she was diagnosed with Hashimoto’s thyroiditis, which is an underactive thyroid condition. Penny’s thyroiditis diagnosis mirrors medical literature that describes a hypothesis of the comorbidity of other autoimmune disorders in addition to alopecia areata (McKillop, 2010; Messenger et al., 2012). In the previous section, I discussed that Penny was also experiencing extreme weight loss and gain from her thyroid condition at this time. And so, Penny potentially had medical implications from her thyroid condition and, based on the hypothesis of the comorbidity of alopecia areata with other autoimmune conditions, it may have been beneficial to know the name and details of her condition that was causing her baldness. However, Penny’s interaction with the medical industry also reflects the paradox of medicalization because, for Penny’s experience, it may have been advantageous to label her baldness, which suggests a need for medical intervention. Furthermore, Penny’s experience with alopecia areata exemplifies the significance of class and how this may factor in to participants’ interactions of the medical industry. Although Penny was interested in learning more

about her condition and baldness, her interaction with the medical industry was dictated by access to insurance.

***Janet's interaction with the medical industry.*** Janet did not really interact much with the medical industry because monilethrix is genetic and not associated with health risks; her onset was in infancy, and her family did not turn to medical intervention, so it was not really her decision. Despite her lack of personal interactions with the medical industry, in her interview, Janet seems to encourage the idea of financial support from the insurance industry for coping and managing conditions, such as monilethrix. In the last section, I included a couple instances where Janet demonstrated financial burdens associated with managing her baldness and condition. Janet's experiences, like Penny's, suggest that there may be a high financial burden to managing baldness from skin and hair conditions, and this can be potentially damaging to participants. Based on Janet's experiences, I consider how socioeconomic status potentially influences participants' interactions with the medical industry. This is a significant point for the medical industry to address when suggesting management strategies around alopecia areata conditions and monilethrix and when allocating funding for patients' needs, desires, and support in the future. While some may view this as increasing the medicalization of female baldness, I argue that these conditions are already medicalized; and therefore, this is not necessarily increasing medicalization, but using experiential knowledge from the patients to gain insight on how the medical industry should consider diagnosing and managing these conditions. The medical industry has already invested in erroneous management and treatment techniques that, oftentimes, are ineffective or participants reject them, so it may be beneficial to all parties to reevaluate the research and funding around these conditions. Through the

medicalization of baldness on female bodies, people rely on the medical industry to provide general answers and support for management. As Janet's experiences suggest, it is a challenge for some families to financially self-sustain these conditions.

As I previously noted, Janet's interaction with the medical industry may also be influenced by the absence of hair loss due to the age of onset at infancy. Janet recognizes that she did not go through hair loss. Therefore, Janet's experience with baldness is different and, suggestively, not as devastating as when she exclaimed, "I can't miss what I never had." This absence of hair loss paired with the family knowledge and history of monilethrix potentially influenced the interaction with healthcare. Furthermore, Janet's interview does not necessarily reflect the prevalence of illness as significantly as participants' experiences with autoimmune alopecia areata conditions. On the one hand, this absence could be because of Janet's minimal interaction with the medical industry, her family history and awareness of the condition, and how she manages her condition with a wig. On the other hand, participants with autoimmune alopecia areata conditions experience onset at all ages in life and there is not necessarily a family history of the condition; and therefore, this may influence them to rely on healthcare more, initially. Although the explicit discussion of illness was limited in Janet's interview, she included a discussion on the mistaken association of her baldness as a result of chemotherapy, which I discuss this in a following section.

Participants' interactions with the medical industry unpack a general need and understanding of their desire for more financial and emotional support from the medical industry, but this is complicated by participants' rejection of illness identities and narratives. In the following sections, I discuss how participants reject identities and narratives of female baldness that equate their baldness with illness, such as the

prevalent association of chemotherapy-induced female baldness. However, participants' interviews also suggest that it is not simply assumptions of cancer that surround their experience of baldness, but that family members also project cultural, generational, and religious understandings of their baldness onto participants. To illustrate, I discuss Emily and Penny's interactions with people who believe their baldness represents illness based on cultural, generational, and spiritual understandings of female baldness in the following section.

**Cultural and generational interpretations of baldness.** Notwithstanding their overall physical health and rejection of illness, Emily and Penny express the challenge of navigating cultural, generational, spiritual and familial interpretations of their baldness and illness. Emily, who identifies as Mexican-American, explains that her "old school Catholic" family in Mexico prayed for her during the time of her hair loss. Her family in Mexico believed her hair loss and baldness meant that she was sick, and Emily explained that she feels her mom is always trying to "fix" her even though Emily does not feel "broken." Emily reflected on how her condition affects her and her mother's relationship when she stated:

[We] don't have a good relationship...because I feel like she's always trying fix me. She's always trying to throw things at me like 'oh, here's a shampoo,' and then I tell her 'like no, mom, it's okay, I'm not gonna put it on.' And then again, 'oh you should, you know, come over here and I'll put it on for you and give you a massage and then I'll take you out to eat- to eat sushi'...'no mom it's okay I'm not going to use the shampoo,' 'but why not,' 'and because I don't want to,' and then she gets to me like 'oh I-I thought that by having a daughter I was going to have a best friend, but I don't--because we argue a lot and that's one of the main arguments and I feel-- and it makes me feel really sad because I feel like when she had me--like when she had a daughter--she had a whole complete different picture of how it was going to be to raise a daughter, you know, and by this happening to me I felt like her whole picture just burned down, and it wasn't the way that she expected it to be and I hate it.

Emily does not specifically state that her mother associates her baldness with illness, but the way her mother continues to suggest treatment options for Emily suggests that she believes Emily needs to be fixed, which implies that something is wrong with Emily in the first place.

On the one hand, Emily's mother believes that Emily's baldness is fixable and reflects Frank's (2006) restitution narrative because this narrative assumes the illness can be cured. On the other hand, Emily's mother does not understand why Emily does not want to try to resolve her baldness and believes that Emily should take ownership over her illness by becoming her own hero, which mirrors Frank's (2006) quest narrative. The quest narrative parallels to ideologies of individualism and heroism, and mirrors a neoliberal, individualistic society, such as in the United States. Ultimately, individualism allows for the shift of blame to be placed on the individual. In the case of illness, individuals receive blame for not being proactive in their health and/or prevention of illness. Once "ill," the individual must seek answers and treatment, but not overcompensate one's health (Varul, 2010). Since Emily is no longer hopeful for regrowth, discards treatment, and rejects any illness identity, other people and the medical industry may interpret her (in)actions as not appropriately performing the expectations of this contested space of illness and health. Accordingly, Emily states, "my mom can't deal with the fact that...I'm happy—I don't know, I really don't know." In other words, Emily's mother's expectations and inability to accept Emily confuse her because she is, now, at a place where she is generally happy with her baldness and condition and does not seek restitution. But her actions are at odds with familial beliefs and expectations; Emily expresses concerns that her mother blames her for her condition because she no longer has faith. For example, Emily no longer attends church;

when her mother asked her to go to church with her and Emily declined, Emily's mother responded with "maybe if you went to church you wouldn't have things like this happen to you." In sum, Emily's mother concludes that Emily's baldness is associated with illness because of her cultural and religious understandings of female baldness.

Similarly, Penny discussed the inability to talk "freely and openly" about her condition and baldness with her grandmother. As mentioned, Penny's mother died when she was 25, and, according to Penny, Penny's grandmother is her "heart." Penny reflected on this when she explained:

when I shaved my head last time and stopped wearing scarves like she would barely look at me and so I like—whenever I saw her I would wear a scarf because she didn't want to see it 'cause she attributed it to me being sick, so um, I tried to talk to her about it again, and I tried to show her a picture and she was—had wanted nothing to do with it, so that's kind of tough, too.

As Penny discussed her grandmother's interpretations of her baldness, it seemed that Penny attributed this to generational understandings of female baldness as illness. Penny has Hashimoto's thyroiditis in addition to alopecia areata, still she does not attribute her baldness to being sick, but her grandmother believes her baldness represents the presence of illness. As Emily and Penny's experiences suggests participants cannot necessarily escape the presumptions of other people including their family members and specifically maternal figures. Therefore, in addition to cultural and generational differences, Emily's mother and Penny's grandmother's understandings of their baldness may also be the result of the loss of an imagined daughter. Since there are societal expectations of girls and women in this society, there are also societal expectations of daughters attached to these ideals, but an analysis on maternal understandings of participants' baldness and illness are beyond the scope of my paper.

Due to assumptions of illness, participants are constantly negotiating assumptions about their health, femaleness, and ability, regardless of their personal rejection of illness. In addition to cultural, familial, spiritual, and generational understandings of baldness, participants expressed that people, oftentimes; presume that participants' baldness is chemotherapy-induced baldness. In the following section, I examine this association to cancer.

**“No, I don’t have cancer, I’m just bald.”** In the interviews, participants explained that others often assume that their baldness and management techniques are because of chemotherapy. Janet, who wears a wig, recalled that in her childhood “every kid that I ever met thought I had cancer...that was always the rumor because they didn’t associate baldness in females with anybody else.” Janet believes that people in her childhood assumed her baldness and reason for wearing a wig was caused by cancer. Janet explained that she grew up in a small, conservative, white town in Ohio; and therefore, she believes people from her childhood has a limited representation of female baldness as chemotherapy-induced. Additionally, Janet believes there is a general lack of knowledge about skin and hair conditions.

In a similar vein, Penny magnifies the association of scarves with cancer by stating “when somebody sees you wearing a scarf they automatically go to cancer so nobody really asks you about it.” Penny’s experience with scarves reflects a culture consumed with visual representations of female baldness as a result of cancer. Breast cancer awareness began as a women-centered, politicized movement to reduce stigmas around breast cancer and to promote breast cancer research (Klawiter, 2008). Recently, the movement has been commodified for neoliberal, consumerist endeavors, and results in a hypervisible representation of chemotherapy-induced female baldness and breast

cancer awareness campaigns. Therefore, female baldness and its associated management strategies such as wigs and scarves are historically and culturally allied with cancer. It appears that in our attempt to make one form of feminist awareness of body issues visible (the changes from breast cancer), we have made another invisible (changes from alopecia).

While all participants disclosed their empathy for people with cancer, oftentimes, “strangers” approach and share their own experiences or a loved one’s experiences of cancer with participants. For some strangers, participants’ baldness, hair loss, or choice of management strategy ignites a connection that leads people to share their own or a loved one’s experience of cancer with participants. However, these disclosures from strangers affect participants. Specifically, this effect can be an intrinsic reward and/or a burden. Ashley shared that women approached her in the past:

Because they thought I went through cancer because they went through cancer, as well, so you know, they want that connection there. And, we’ll sit and we’ll talk, we’ll be in the middle of a supermarket talking to someone for twenty minutes just about that connection. I may not have cancer, but I still know what it’s like to go through things.

Through the shared experience of baldness, Ashley and these women were able to “automatically click.” Although not ashamed of or opposed to share her condition, Ashley has to disclose that she is not a cancer survivor, but bald due to alopecia areata. For Ashley, these connections are a positive outcome of her baldness and condition: “...to be able to click through something that like that and be there you know it’s a big thing.”

Similar to Ashley, Emily shared experiences of people interacting with her on the presumption that she has or had cancer. Compassionately, she reflected on this point when she explained

I have had people come up to me and hug me...like random strangers—ladies—that cry in front of me because their daughter, their son and I-I do feel bad because...I-I feel for them that someone passed away, you know, and then I'm just standing in front of them like 'no I don't have cancer, I'm just bald.'

Emily recognizes the fatality and severity of cancer and therefore is empathetic for the stranger who has placed an unknown burden onto Emily. Because of the initial association with cancer, Emily must disclose her condition and baldness. In other words, the hypervisibility of chemotherapy-induced baldness paired with the cultural script that associates female baldness and scarves to chemotherapy-induced baldness is extremely pervasive and contributes to Emily's experiences of disclosure. This hypervisibility creates compelling situations where participants potentially have to explain why they are bald, but through this explanation participants potentially subvert their own conditions.

Similarly, Penny explained that others' initial assumptions about her as a person with cancer sometimes position her to undermine her own experiences with baldness. For example, Penny shared that, when she first shaved her head and wore scarves, people were initially afraid to ask about her baldness. However, once they found out her baldness was the result of alopecia areata and not symbolic of cancer they were relieved with this information because "it was to the point where it was like at least—okay—at least Penny doesn't have cancer." The way Penny told this story suggests that this thought process of "at least Penny doesn't have cancer" fails to recognize the struggles that Penny experience because, accordingly, all that matters is that it is not cancer.

While all participants infer that cancer is worse given that it is life threatening and all participants imply that their lives "could be worse," some interactions create situations where participants feel that other people challenge or invalidate their

experiences of baldness. However, as participants' interviews suggest their lived experiences surrounding their experience of baldness from skin and hair conditions are more complex than "just bald," even though they do not face a life-threatening condition, such as cancer. While participants repeatedly empathize with people with cancer, they seek awareness about their conditions and baldness and the desire to share their own experiences because as Emily stated "it's like there's nothing in between and I hate that because it's like we should be recognized, too—because we are different, and we will always and forever have to live with this." Although participants resist the narratives and assumptions of illness around their baldness, as the aforementioned discussion implies, there are benefits and burdens associated with accommodating illness narratives in this society, such as acceptance and potential support from the healthcare industry.

## **Chapter Five: Conclusion**

The main objectives of my study were to share women's experiences of baldness from skin and hair disorders and to promote a more inclusive approach to female baldness and standards of beauty. In order to achieve my objectives, I found qualitative research and feminist research methodologies useful for my study, especially since qualitative approaches to understanding experiences of baldness from skin and hair disorders are minimal at best. Specifically, my study employed interactive interviewing to gather data and the data was organized in themes through interpretive phenomenological analysis. Based on my analysis, I divide participants' information into two themes, which include (a) navigating ideal femininity and (b) negotiating assumptions of illness. Additionally, participants' experiences of baldness from skin and hair disorders are complex and elucidate how participants accommodate and/or resist hegemonic notions that surround femininity, illness, and female baldness.

Participants' experiences suggest that, despite participants' intent in accommodating or resisting hegemonic notions, societal expectations hold participants accountable to these performances. Furthermore, participants' experiences reveal that participants do not initially have the luxury of choice in their baldness. For instance, skin and hair conditions, such as autoimmune alopecia areata conditions and monilethrix, are of the body and dictate the level of choice that participants actually have in their baldness. Moreover, the level of choice is also different for women who experience baldness from chemotherapy since cancer is a condition of the body as well.

Because of participants' initial lack of choice, understanding, and control over their baldness, it is imperative to not erase or glamorize the realities of living life as a woman who is bald in a society that shames, polices, and punishes female bodies that do not submit to dominant standards of femininity. Future research should recognize that there is an immense difference between bald by choice and bald by a condition of the body or chemotherapy. This difference is crucial because women who are bald by a condition of the body experience events and emotions that women who are bald by choice do not necessarily experience. In general, the participants described experiences including bullying, depression, girl hate, feelings of unattractiveness, low self-worth, internalization, and fear of exposure when navigating their performance of the feminine ideal and negotiating assumptions of illness. As previously noted, there are alternative ways of "doing" femininity and therefore women who *choose* baldness may be more open to challenging hegemonic norms.

Mirroring the first theme, participants' interviews disclosed that, in certain contexts, there are punitive consequences for not performing the ideal femininity; and therefore, this is another factor in participants' accommodation and/or resistance of the feminine ideal. To illustrate, workplace expectations of professionalism and the feminine ideal was a prominent theme that participants discussed in relation to their management techniques. To avoid societal or punitive consequences, sometimes participants changed their management technique at their workplace or during interviews to appease the institutionalized patriarchal power that demands the feminine ideal. In addition to the feminine ideal, participants' experiences also explicate how other axes of life, such as age, class, race, geographical location, and religion influence how, when, and why participants navigate their performance of the feminine ideal as

well. However, based on the participants' demographics coupled with the experiences they shared with me, my findings focused more on age and class. Future research on women's experiences with baldness from skin and hair conditions should integrate analyses specific to the multiple subjectivities of women's lives. Specifically, future research should continue qualitative approaches to women's experiences of baldness from skin and hair conditions. Nevertheless, I acknowledge that qualitative approaches to research have limitations as well. For the scope and purposes of my study, the sample size of four participants is sufficient. However, future research should consider expanding the sample size in order to compare experiences across a wider sample and demographic. Qualitative research is unable to generalize data outside of the study; and therefore, my study cannot make claims outside of participants' experiences.

Regarding the second theme of negotiating assumptions of illness, participants' experiences demonstrate that even though they reject illness identities and narratives, there are cultural, generational, and religious understandings of baldness that position participants' baldness within illness. For instance, the cultural prevalence of chemotherapy-induced baldness on female bodies situates participants' baldness within this narrative and representation of female baldness. Additionally, Emily and Penny's experiences demonstrated the impact of familial, generational, and spiritual explanations of female baldness and illness. Furthermore, participants experience their conditions and baldness within a society that has already medicalized female baldness and their conditions based on the historical and cultural expectations of female bodies, beauty, and sexuality. Although participants do not feel or identify as ill, this medicalized understanding of female baldness, prevalence of female baldness and illness, and participants' needs and desires constitute interactions with the medical

industry. However, participants' interactions with the medical industry are negative or ineffective. Thus, future research should continue to examine women's experiences who are bald from skin and hair conditions in order to assess medical needs and desires.

In the theoretical framework, I discussed that theories and scholars of disability influenced my research. My prior knowledge and own experiences with female baldness provided insight on the relevance of disabilities theories and coming out narratives to women's experiences of baldness from alopecia areata, alopecia totalis, alopecia universalis, and monilethrix. While I do not claim that these conditions are disabilities, participants' experiences reveal the significance of the intersection of the medicalization of female baldness and the historical expectation of female bodies to perform the feminine ideal. Furthermore, this intersection exposes the ableist assumptions rooted in dominant standards of femininity and beauty within the United States. According to medical literature and participants' experiences, these conditions have minimal medical symptoms outside of alopecia and the emotional and mental impact of the conditions and baldness. It is appropriate to consider disability theories because female baldness from these four skin and hair conditions reflect a body variation that society historically constructs as an illness. However, participants' experiences exposed that society reduces the significance of their conditions by not considering and integrating the needs and desires of women who have these conditions. Therefore, future research should continue analyzing women's experiences of baldness from skin and hair disorders through disability theories.

Despite the accountability and discourses that prevail around hegemonic notions, participants resist and take control over their bodies, baldness, conditions, and femininity. Penny and Ashley shaved their heads and accepted their baldness in spite of

a culture that denounces female baldness as deviant and unattractive. Similarly, Emily has been experiencing regrowth in her eyebrows, but stated that she plucks them out despite desiring eyebrows. While plucking leaves Emily with no eyebrows, the act of plucking her eyebrows represents her taking control of her condition. Janet expresses that she has come to peace with her baldness and condition, and looks forward to sharing her experience. While enmeshed in a society that demands an unrealistic standard of perfection of female bodies, participants learn to live unapologetically as women who experience baldness from skin and hair conditions by taking control over their conditions and redefining their understandings and performances of femininity.

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