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## Chemotherapy-Induced Alopecia and Quality-of-Life: Ovarian and Uterine Cancer Patients and the Aesthetics of Disease

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Chemotherapy-Induced Alopecia and Quality-of-Life:  
Ovarian and Uterine Cancer Patients and the Aesthetics of Disease

by

Meredith L. Clements

A dissertation submitted in partial fulfillment  
of the requirements of the degree of  
Doctor of Philosophy  
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## DEDICATION

This work is dedicated to the ovarian and uterine cancer patients who participated in this study. Thank you. This type of work cannot happen without you. I am indebted to you and the patient community you represent. To my parents, Drs. Arthur and Patricia Clements, whose intellectual curiosity inspired my own. Thank you for supporting my dreams. It brings me great joy to be your daughter. Thank you, Claire Clements, for your constant love and encouragement. It is a blessing to have a sister who is also my best friend. To my mentor and source of ambition, Lori Roscoe. Thank you for the years of friendship and detailed reviews. Your editing is an integral part of this project and my learning process. I am grateful for your guidance.

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## ABSTRACT

This study is an examination of ovarian and uterine cancer patients' perceptions of chemotherapy-induced alopecia and how it impacts quality-of-life over the course of chemotherapy. The chapters in this dissertation address the following research questions: How do ovarian and uterine cancer patients communicate about their experience of alopecia over the course of chemotherapy? How does chemotherapy-induced alopecia influence patients' understandings of quality-of-life? Longitudinal interviews were conducted with a patient population of twenty-three, and each patient was interviewed at least twice over the course of chemotherapy. The data set was composed of fifty-five interviews, and a thematic analysis was performed across interview transcripts.

Analysis of the data revealed four themes: 1) chemotherapy-induced alopecia and quality-of-life; 2) the "mirror moment"; 3) performance of social roles; and 4) gendered visibility. Data indicate ovarian and uterine cancer patients' experienced substantial daily distress related to chemotherapy-induced alopecia. The ability to perform social roles deemed important to patients' quality-of-life such as the familial roles of partner and mother/grandmother were negatively impacted by hair loss. Patients' distress concerning alopecia was strongly connected to the ability to function in the public sphere without feeling approachable or being approached by "strangers" because of their alopecia.

Clinicians might consider repeatedly asking about chemotherapy-induced alopecia over the course of chemotherapy, both because it could help patients cope with the side effect and because it may generate dialogue related to other important concerns late-stage cancer patients may feel are too trivial to mention in clinical discussions. Women's social and familial roles may be impacted by alopecia and chemotherapy in unique ways that deserve additional study.

CHAPTER ONE:  
COMMUNICATION, CHEMOTHERAPY-INDUCED ALOPECIA,  
AND QUALITY-OF-LIFE

**Introduction**

*“There is an immense connection between hair loss and quality-of-life...The Bible says hair is your crowning glory...When I first shaved my head I thought, gee, I look like my father, and I put my scarf on immediately...Hair loss did not become a concern until after the third round [of chemotherapy]” (Patient 16\_2).*

*“For me, [hair loss] matters because of the privacy issue...there are some assumptions that are being communicated...I know I’m not going to recover [and I spend] too much time explaining. I have a life. I have a career” (Patient 13\_2).*

*“Your head is speaking for you” (Patient 21\_1).*

*“I’m not around people without my hair [wig] because I don’t like to be without something on my head. I don’t look at myself. It’s just a constant reminder. That’s all” (Patient 6\_2).*

Chemotherapy-induced alopecia, or hair loss during cancer treatment, is often understood as the most significant change in appearance for cancer patients (Erdos, 1992). Inspired by Erdos’ (1992) argument, Pickard-Holley (1995) positions hair loss as the most traumatic side effect for female cancer patients, suggesting a need for more research to identify the multiple ways in which alopecia impacts quality-of-life over the course of treatment. Batchelor’s (2001) research reports hair loss as ranking third among “the most distressing effects” of cancer treatment with nausea and constipation as first

and second. Similarly, Mulders, Vingerhoets, and Breed (2008) report breast cancer survivors ranking hair loss among the fourth highest of concerning side effects of chemotherapy with nausea ranking fifth and fear of metastases, fatigue, and consciousness of being vulnerable ranking first, second, and third.

Existing research (Can et al., 2012; Erol et al., 2012; Firth et al., 2007; Jayde et al., 2013; Pickard-Holley, 1995) suggests there are complicated connections between alopecia and quality-of-life (QoL) warranting further examination. Research on quality-of-life has been advanced by studies (see Gupta et al., 2013) arguing for the importance of measuring quality-of-life over time. Most attempts to measure “quality” in healthcare settings reduce it to a quantifiable, single point in time measurement. A more effective and valid analysis of “quality” requires qualitative measurement that takes place over time. This makes sense when considering the subjective nature of “quality,” making it more difficult to measure than other variables in healthcare such as cost, speed, or length of time that are more easily quantifiable. As 21<sup>st</sup> century medicine continues its evolution toward individualized patient care, the healthcare industry is looking for ways to better balance the need for high quality, patient-centered care with its “cheaper, faster, better” approach to practicing modern medicine.

An issue worth noting in Gupta et al.’s (2013) argument for longitudinal testing of quality-of-life is their use of the QLQ-C30, a well-known and widely used QoL questionnaire (see Aaronson et al., 1993). The QLQ-C30 *excludes* alopecia from its list of measurable symptoms of chemotherapy related to QoL, yet “financial difficulties” and “loss of appetite” are examples of what factors are included. Gupta et al.’s (2013) research has bolstered the argument for longitudinal analyses, yet there remains a need

for a more thorough, empirical examination of how female cancer patients describe quality-of-life. An analysis of how patients communicate their experiences of chemotherapy-induced alopecia may provide insight into ways patients conceptualize quality-of-life, thus gaining a better understanding of this element of cancer care.

This dissertation positions communication in the center of the research problem with the intention to examine patterns of connection and/or disjunction between alopecia and quality-of-life so practitioners can better identify and treat patients who will or who are experiencing distress related to alopecia. This aim of this project is especially important when the population of interest includes ovarian and uterine cancer patients in the late stages of their disease who are coping with the surgical removal of internal organs related to their sex/gender along with the external loss of their hair, a gendered identity marker (Batchelor, 2001; Cline, 1984; Frith, Harcourt & Fussell, 2007; Lemieux et al., 2008).

Female cancer patients are particularly affected by changes in appearance because cultural norms circumscribe what is acceptable and expected of women with cancer (Hooper, 1994; Price Herndl, 2006). Baldness and other visible bodily changes such as scars, weight gain or loss, and lopsided figures “function like billboards” (Gubar, 2014), signaling a woman’s status as a cancer patient. Some feminist critiques (Lorde, 2009) call for resistance against social norms reinforcing appearance as a priority, especially for women facing serious and life-threatening diagnoses of cancers. Patients who subscribe to Lorde’s (2009) argument against cranial prostheses (wigs) may be determined to resist “cosmetic deceptions” (Ehrenreich, 2009, p. 30) and work “to expose themselves publically

in order to witness and protest the epidemic” while others, Gubar (2014) explains, “become agoraphobic, unwilling to leave home.”

Patients treated in major cancer research institutes, such as the site of research for this dissertation, are seriously ill and are often classified as complicated cases. The ovarian and uterine cancer patients participating in this dissertation research have especially valuable perspectives on managing hair loss because of the severity of their type of cancer and the late stages of their disease. Some participants are experiencing recurrence and have an unfortunate familiarity with hair loss. Others know they “will not recover” and are making decisions regarding how they want to look during their final phases of life. For the patients experiencing remission, they are making sense of “what recovery looks like” in terms of their mind, body, spirit, and appearance.

This dissertation research uses an interpretative approach and longitudinal interviewing to examine the ways women communicate about chemotherapy-induced alopecia while undergoing treatment for ovarian or uterine cancer. In the following section, extant literature relevant to the problem of inquiry is reviewed. Goffman’s (1963) foundational work on stigma is used to conceptualize how social norms potentially influence how patients interpret their experiences of chemotherapy-induced alopecia. The social implications and the science of chemotherapy-induced alopecia are discussed along with gender and technology. Lastly, quality-of-life literature is examined to demonstrate the importance of its connection to patient experience, and current methods of assessing quality-of-life are challenged. A rationale for the research project is provided prior to concluding the chapter.



CHAPTER TWO:  
LITERATURE REVIEW AND RATIONALE

**Introduction**

While ovarian and uterine cancer patients' perceptions of chemotherapy-induced alopecia and its negative impact on quality-of-life have been documented (see Batchelor, 2001; Choi et al., 2014; Dua et al, 2015; Freedman, 1994; Frith et al., 2004; Hansen, 2007; Hesketh et al., 2004; Jayde et al., 2014; Lemieux et al., 2008; Munstedt et al., 1997; Pickard-Holley, 1995; Rosman, 2004; Yeager & Olsen, 2011), there remains a need for more research examining the experience of alopecia over time and how patients describe quality-of-life in the context of undergoing chemotherapy. Health communication can make a significant contribution to the body of mostly clinical research examining how patients negotiate what it means to cope with a side effect that can be understood as speaking for you. Chemotherapy induced alopecia (CIA) is a publically visible, aesthetic transformation involving sensemaking (Weick, 1995) on a personal and social level.

Given the interdisciplinary interest in patients' perspectives of chemotherapy-induced alopecia and because my primary field of study has yet to produce patient-centered research specific to chemotherapy-induced alopecia, I review clinical research alongside work in social science and the humanities to help formulate research questions

that may benefit researchers across disciplines as well as highlight the usefulness of a communication studies approach. The literature review is divided into three sections with multiple subsections. Relevant literature on the significance of chemotherapy-induced alopecia and the gendered elements of hair loss are discussed. Goffman's (1974) work on stigma and research applying his theory to healthcare are presented as a framework through which the research problem may be conceptualized. Lastly, quality-of-life (QoL) studies useful to alopecia and side-effect management are presented as well as critiqued for how they measure subjective variables.

### **Chemotherapy-induced alopecia (CIA)**

Chemotherapy and other appearance altering cancer treatments such as radiation or steroid hormones are emotionally, physically, and psychologically taxing and demonstrate the difficulty of being treated for a serious disease (see Wackers, 2015). Though there are different types of chemotherapy, the treatment itself can be broadly understood as a drug therapy that inhibits cell division or growth. One of the most common cutaneous side effects, meaning a side effect that affects the skin, is alopecia (Dunagin, 1982). Hair is often lost on all or most places the body has it, including the head, face, arms, legs, pubic area, and underarms (www.cancer.net, 2015).

Understanding chemotherapy as a process helps bolster the argument for examining hair loss as a process (see Erol, Can & Aydiner, 2012). Chemotherapy involving carboplatin and paclitaxel, for example, typically involves a time commitment of 4 months or more. In addition to the time commitment and its disruption to everyday routine, the severity of treatment and its impact on the body varies over the course of treatment. The results of Munstedt et al. (1997) longitudinal survey provide a framework

to argue for CIA as a process that should be analyzed over time. Twenty-nine gynecologic cancer patients were surveyed before, during, and after hair loss using two scales (Frankfurt self-concept [FSKN] and Frankfurt body concept [FKKS]) to measure changes in self-concept and body image. Following the third round of surveys administered during the regrowth stage of hair loss, 73% were less self-confident than before treatment, demonstrating the ongoing difficulty of coping with appearance altering side effects.

Munstedt et al. (1997) would have benefitted from incorporating interviews into their method for a more in-depth analysis of how perceptions of self change over time, especially considering how practical this would have been with their number of participants (n=29). Munstedt et al.'s (1997) work has been cited by quantitative and qualitative researchers for their finding of 47% of participants ranking hair loss as the most traumatic side effect of chemotherapy. This contribution aside, their emphasis on longitudinal method has not been widely adopted as standard practice for analyzing patients' perceptions of hair loss. For example, qualitative researchers Power and Condon (2008) use Munstedt et al. (1997) to support an argument for the importance of studying women's CIA but do not perform a longitudinal analysis, which is contrary to the study they are referencing.

**The science of hair loss.** Hair loss becomes more noticeable when it falls out in gradual sections, however not all chemotherapy causes hair loss, and not all patients who undergo treatment lose their hair to a degree where thinning occurs at a noticeable rate (www.cancer.net, 2015). There are two types of chemotherapy-induced alopecia – telogen effluvium and anagen effluvium (Yeager & Olsen, 2011). Telogen effluvium is

less aggressive than anagen effluvium, usually resulting in significant thinning, where a patient can lose about fifty percent of the hair during chemotherapy. This type of CIA is less noticeable to the public eye than anagen effluvium, which often results in baldness. According to Yeager and Olsen (2011, p. 433), anagen effluvium is a commonly associated with chemotherapy “because it is caused by drugs that target rapidly proliferating cell populations and attack neoplastic cells and rapidly growing normal cells like the hair matrix cells in anagen.” Anagen is one of the three phases of hair growth and is the phase during which active growth takes place (Schwartz & Gascon, 2016). Chemotherapy weakens the hair’s anchoring to the point that it falls out from the scalp or breaks off when it reaches the surface of the scalp.

Paclitaxel (the generic name for taxol) is one of the most well –known chemotherapeutic agents causing hair loss. It results in a profound and often complete loss of hair (anagen effluvium) and occurs within approximately two to three weeks after starting chemotherapy. It should be noted some patients do not lose their hair until one or possibly two months into treatment. Once the anagen (actively growing) phase hair shafts are lost, the patient’s hair will remain in the telogen phase, which is a period of no growth, and this will last until chemotherapy is completed. Oftentimes, the anagen phase is quite slow, so a patient’s “prechemo” hair length often takes years to “regrow” and her hair usually does not return the same as it was (e.g., straight, light brown hair on the head could return as grey and wavy and take months to grow an inch in length).

To further complicate the way a patient can experience hair loss, it is important to acknowledge the “sandwich method,” when surgery is sandwiched in the middle of chemotherapy. During the surgery phase, a patient’s alopecia will stop and a bit of hair

may return only to have it fall out again when she restarts chemotherapy. No literature could be found specific to a patient population enduring alopecia and the sandwich method, rather most literature focuses on hair loss and distress (Freedman, 1994; Hesketh et al., 2004; Kaderman, Kaderman, & Toonkel, 1999; Poulson, 1998) do not make distinctions between the sandwich method and regimens involving surgery before or surgery after chemotherapy.

**CIA: An interdisciplinary problem of interest.** The latter half of the twentieth century marked a time of emerging interest in examining alopecia and its effects on patients' well being. Research in the 1980s (Cline, 1984) focused on preventing hair loss and set a foundation upon which scholars could argue for in-depth analyses of hair loss as an emotional experience (Koszalinski & Williams, 2011; Pickard-Holley, 1995; Williams et al., 1999). Narrative analysis (Williams et al., 1999) along with qualitative inquiry (Freedman, 1994) and mixed methods using smaller sample sizes (Carpenter & Brockopp, 1994; Munstedt et al., 1997) became popular ways to research chemotherapy-induced alopecia, generating foundational insight cited across disciplines interested in oncology, hair loss, and patient care.

Research using smaller sample sizes to analyze the nuances of CIA was not reserved for patients with one form of cancer, thus providing a range of perspectives from patients with various degrees of severity. Freedman (1994) interviewed breast cancer patients about losing their hair, focusing mainly on the symbol of hair loss and the idea of womanliness in ways that impact the meaning of being a breast cancer patient. As discussed earlier, Munstedt et al. (1997) survey analysis of 29 gynecologic cancer patients' perspectives demonstrated CIA's effects on self-concept and body image.

Williams et al. (1999) used a narrative approach from the field of nursing to interview 15 patients with different cancers (13 women and 2 men). Their findings presented hair loss as an experience that affects everyday life and personal identity. Williams et al. (1999) use of “experience” was deliberate and foundational for conceptualizing patients’ hair loss as such.

Like Williams et al. (1999), Carpenter and Brockopp (1994) also analyzed the perspectives of patients with different cancers. They interviewed 30 women with varying degrees of hair loss (due to dissimilar chemotherapies). While participants reported lower self-esteem during alopecia when compared to pre-diagnosis, Carpenter and Brockopp (1994) found participants making distinctions in the numbered responses between lowered self-esteem and low self-esteem, arguing for more research on patient-specific interventions. Despite the existing literature, an interdisciplinary focus on ovarian and uterine cancer patients’ experiences with hair loss remains limited and methods for collecting data need a stronger emphasis on longitudinal interviewing.

The vast majority of research on chemotherapy-induced alopecia is generated by healthcare professionals in the fields of dermatology (Chon et al., 2012; Yeager & Olsen, 2011) and oncology (Frith et al., 2007; Gunnars et al., 2001; Hesketh et al., 2004), including nursing in oncology (Borsellino & Young, 2010; Can et al., 2012; Cline, 1984; Freedman, 1994; Lemieux et al., 2008; Wagner & Gorely, 1979; Williams et al., 1999) and psychology in oncology (Choi et al., 2014; Dua et al., 2015; Koszalinski & Williams, 2012). Research efforts made by scholars outside health sciences are best represented by Hansen’s (2007) ethnography of Danish rehabilitation courses with women cancer patients and Rosman’s (2004) qualitative study of stigma with lung and breast cancer

patients in a Parisian cancer hospital. Excluding Williams et al. (1999), most of the heavily cited literature on chemotherapy-induced alopecia and patient experience comes from Western nations outside the U.S. (e.g., Batchelor, 2001; Freedman, 1994; Frith et al., 2007; Lemieux et al., 2008; Munstadt et al., 1997).

To date, there are few health communication studies in the U.S. researching chemotherapy-induced alopecia. Such an absence suggests the existing interest in producing qualitative data on hair loss and patient experience will benefit from a health communication studies perspective focusing on the ways in which language and relationships constitute meaning making over time. Such a perspective will enable an analysis of how ovarian and uterine cancer patients communicate about CIA how experiencing hair loss influences their quality-of-life.

**CIA: Gender and Loss of Privacy.** Distress associated with hair loss is discussed as a reactive process (Batchelor, 2001) depending on how important hair is to a patient in terms of how it relates to her identity (Williams et al., 1999) or “body perception” (Miller, 1991). Clinical research (Lemieux et al., 2008), social science (Hansen, 2007), and humanities-based research (Freedman, 1994; Hooper, 1994; Redgrave, Clark & Lerner, 2004) argue chemotherapy-induced alopecia is a critical moment in the cancer experience because the loss places women patients in a position of having their bodies signal their health status.

Freedman’s (1994) work on hair and social significance argues hair –particularly women’s hair– is a socially and culturally defined characteristic of personal choice and expression as well as a symbol of political and religious beliefs. Hair can be viewed as both a private asset and a public symbol and so can the loss if it (Firth, 1973). Hair can reflect

international trends of personal expression (Batchelor, 2001), signaling gender, age, health status, and group membership (Pickard-Holley, 1995). The idea of hair or shaved heads as a “personal expression” mentioned in Pickard-Holley’s (1995) work is misleading when applied to chemotherapy and cancer patients because it implies a sense of agency that many ovarian and uterine cancer patients are not able to enact in the context of their hair loss. Explained by Holmes (2014), “female baldness is an antithesis to the feminine ideal” (p. 66). Being bald is highly gendered because it is a socially constructed aesthetic carrying well-known Western expectations that are projected onto female bodies (Holmes, 2014).

The argument alopecia is a women’s issue has been complicated by research conducted in the Middle East (Can et al., 2013). Using in-person interviews and two scales (Nightingale Symptom Assessment Scale and Body Image Scale) Can et al. (2013) compared a large sample of Turkish men and women with different forms of cancer to assess their experience of CIA. Their findings suggested hair loss lowers patients’ body image regardless of sex, yet women reported lower scores than men regarding how hair loss impacted their psychological well-being. While this study bolsters the argument for hair loss impacting body image across the sex and gender spectrum, the stronger connection women make between body image and psychological well-being suggests alopecia is a sexualized and gendered issue. Considering the conceptual overlap between psychological well-being and quality-of-life, I interpret Can et al.’s (2013) findings as a base from which to argue for potential connections between hair loss and quality-of-life.

Can et al. (2013) claim to analyze the “experiences of chemotherapy-induced alopecia,” yet they do not adequately consider the communicative aspects of an



“experience.” The missed opportunity to engage patients’ perceptions of social norms and how they relate to baldness is demonstrated by their conclusion, “psychological well-being of women was lower than that in men because the incidence of alopecia was higher in women” (Can et al., 2013, p. 255). The rate at which alopecia occurs does not explicate the gendered and relational elements informing how women associate being bald with a lower sense of well-being to a stronger degree than men. Can et al.’s (2013) well-founded attempt to examine gendered differences and patient experience demonstrates the need for interdisciplinary scholarship that includes health communication scholarship. Unfortunately, there is a lack of health communication research for scholars such as Can et al. (2013) to reference for methodological inspiration. An analysis of experiencing CIA should account for the complex relationship between social norms and expectations (e.g., appearing feminine) and personal struggles with illness (e.g., the loss of control).

Hair is a body part over which it is assumed one has at least partial control. The loss of an asset suggests a forfeiture of ownership and control over the asset. Hair loss transitions the patient out of the private sphere and into the public domain, signaling her status as a cancer patient (Firth, 1973). Continuing to follow Price Herndl’s (1993) argument against blurring distinctions, it is important to recognize not all women cancer patients are stigmatized to the same degree, nor are all women equally concerned about hair loss.

Chemotherapy-induced alopecia may be a reactive experience in that each patient has her own reactions to a changing appearance. Being bald in Western society does not fit with normative standards of gendered aesthetics. As members of Western society, ovarian

and uterine cancer patients are at least partially aware of these social standards (see Firth, 1973; Power & Condon, 2008). Because of this awareness, some patients may describe how they manage hair loss in proactive terms. More research needs to be conducted examining the differences in tone and language patients use to describe alopecia. An example of a proactive response or a reactive response to CIA is the timeframe during which a patient might purchase a wig and why. Ovarian and uterine cancer patients' decision-making regarding purchasing and wearing head coverings has not been fully addressed in existing literature. Knowing when, how, and why these choices are made may provide a more complete understanding of the ways patients manage alopecia outside the clinic.

There is little research discussing whether cancer patients view CIA as a permanent or temporary loss (or a combination of the two), so it is difficult to determine whether juxtaposing hair loss in permanent or temporary terms is a beneficial way to investigate the problem. In contrast to the norm, Redgrave et al. (2004) directly address the emotional complexity of mourning a temporary loss. Their narrative approach highlights the struggle of understanding why a temporary loss is difficult when "the big picture" of cancer "should" remain at the forefront of a patient's concerns (Redgrave et al., 2004).

Narrowing the focus of hair loss to the moment of her head shave, Redgrave et al. (2004) use photography and conversations with her adult daughter to document the experience. Redgrave's head shave is referenced throughout the latter half of the text and is specifically addressed in two pages (p. 54-55). The top portion of the two pages features a series of photos taken before, during, and after the head shave. Redgrave is

shown sitting, removing her wig while looking in the bathroom mirror. Her daughter stands, holding electric clippers. The camera is behind the two, out of view from the mirror's reflection. The following text is displayed below the photos:

"I know it will [be okay], I know it will...when it comes back, it'll be like a new life won't it...I don't know why it's so hard, [daughter]. I don't know why. Because you don't feel like yourself [her daughter says]...you're still you. I know. That's it. I think. Its true" (p. 54)...[but] when it's coming off in the shower, it's, it's like you can't...it's like your whole self is falling apart. It's just...this [head shave] is better...I can handle this better [than hair loss]" (p. 55).

Concern for losing one's hair during treatment *should* be an acceptable emotion to communicate, yet it can be interpreted as superficial by society, loved ones, physicians and providers, and even the patient herself (see Ehrenreich, 2009). Though superficial concerns are often part of everyday life, the "life-or-death" situation cancer represents often elevates patients, particularly women, to the status of a "fighter," transforming the role of performing "patient" into a fighter who focuses on survival and disregards the aesthetic (Ehrenreich, 2009, p. 30; Lerner, 2004).

**Hair loss and technology in women's oncology: Hindrances and possibilities for communication.** One of the primary responsibilities of medicine is to continue developing and redeveloping technological procedures for treating forms of cancer (Mukherjee, 2010). Aggressive drug treatments of the early 1900's helped advance chemotherapy, while surgical procedures in the late 1800's such as the radical mastectomy helped technologize women's health. Even so, modernization through chemical and surgical innovation does not coincide with advancements in interpersonal

or organizational communication among doctors and their patients (Lerner, 2014). For instance, the outcome of a radical mastectomy involves physical disfigurement so severe that 20th century medicine shifted the surgery out of standard practice, reserving it for extreme cases. Unfortunately, it took approximately 100 years for the medical community to reach this consensus partially because physicians who questioned the need for such a procedure were slow to communicate their concerns or did so in an ineffective manner.

Questioning the methods used to move women's oncology forward is difficult because it suggests healthcare practitioners actively recognize a problem exists within the system (see Hughes, 2004). Questioning routine, especially a highly technical one such as a surgery or a drug treatment is difficult partially because it takes time (Hughes, 2004). For instance, wondering how the disfiguring procedure of a radical mastectomy has become standard procedure performed on breast cancer patients would require slowing down the healthcare system and taking time to communicate concerns. This action slows down production and, as a result, slows the delivery of health care.

In the context of hair loss, which is a less technical, non-life-threatening side-effect of a larger process that is both technical and life-threatening, Yeager and Olsen (2011) report patients do not receive enough counseling time, nor do they have the opportunity to ask physicians to evaluate the feasibility of a chemotherapy regimen that incorporates scalp cooling technology to prevent hair loss. Bringing patients into the decision-making process can mean slowing down the pace of medicine, which may seem difficult in the modern/post-modern era of rapid technological growth (Lerner, 2014) but

may yield higher returns in patient comprehension and patient-practitioner communication (Mulders et al., 2008).

There is a scarcity of health communication research on old or mundane technology. Saunders' (2008) ethnography of diagnostic communication within computerized tomography (CT) suites takes place when CT scans and scanning rooms were more relevant and necessary than they are in 2017. At the time of his examination, CT scans were considered a mundane technology, making the ethnography less about the technology itself and more focused on human interaction and the ways medical practitioners incorporate technology into the decision-making process. With the ability to share CT scans electronically, the scanning room is used less as a space of in-person, shared decision-making and more as a space for processing the test.

A wig is an example of an old and mundane technology. It is certainly less obvious than a CT scan, but it is a health technology nonetheless. Depending on the health insurance provider, a physician can write a prescription for a "cranial prosthesis" to cover some of the cost. The classification of "prosthesis" elevates a wig's status from a beauty product to a more formal health technology. Conceptualizing a wig as a technological intervention for cancer patients further legitimizes the practice of covering women's baldness. This reinforces traditional hegemonic standards of gender performance while also providing more options to patients who value aesthetic-related health interventions. Access and cost remain issues. The classification of a prescribed "prosthesis" helps increase the cost of wigs, widening the gap of accessibility to wigs for women without insurance or those who have limited coverage.

How healthcare technologies are understood and used evolves over time (Hughes, 2004). It is useful to have research like Saunders' (2008) examination of CT suites to help the field of healthcare chart its evolution. How might healthcare researchers chart the technological evolution of non-technical technologies such as wigs? It is worth it to approach the problem of hair loss in a way that accounts for embodiment and technological influence? The subset of chemotherapy-induced alopecia research examining scalp cooling technology argues it is.

Scalp cooling is the most popular and well-researched method for preventing chemotherapy-induced alopecia (Yeager & Olsen, 2011). Depending on perspective, scalp cooling could be seen as a useful form of preventing hair loss or a risky and burdensome approach for those who want to preserve what needs to be lost during chemotherapy. Most physicians in America prescribe cranial prosthesis to ovarian and uterine cancer patients as opposed to scalp cooling technology. Many major cancer centers do not provide information on prevention methods, suggesting alopecia is a common and expected part of chemotherapy and patients are responsible for accepting and managing. Scalp cooling and cold caps are not a focus of this dissertation, yet it is a form of intervention worth presenting in this literature review because of its connection to managing one's appearance.

**Cold cap technology: An option not heavily pursued in America.** Scalp cooling by way of cold cap technology represents an interstice between cancer treatment and aesthetics. Scalp cooling has been researched for over forty years with the majority of studies conducted in Europe (e.g., Lemenager, et al., 1997; Peck, Mitchell & Stewart, 2000). One way to "cool" the scalp during chemotherapy is by wearing a cold cap, which

is essentially a pieced together helmet of freezing cold gel packs. Scalp freezing is a more accurate description than “cooling,” as these gel packs are placed on the patient’s head at -35 degrees F. In Lofti-Jam et al.’s (2008) review of non-pharmacologic prevention methods, they argue scalp cooling is effective, suggesting it be recommended to patients who want to pursue hair loss prevention. Yeager and Olsen (2011) classify scalp cooling as an advantageous “non-camouflage” treatment method, unlike turbans, wigs, and scarves, which function to camouflage instead of prevent.

Incorporating cold cap technology into the regimen of chemotherapy might preserve a patient’s hair follicles, allowing her to keep most of her pre-chemotherapy hair (Grevelman & Breed, 2005; Peck et al., 2000). The process of administering the cold cap is complicated. Legally classified in the United States as personal property, cold caps are the patient’s responsibility ([www.rapunzelproject.org](http://www.rapunzelproject.org), 2015). Hospitals and cancer centers are not liable for cold caps nor do they regulate how patients use them, yet the institution and its employees are expected to accommodate the caps because they are classified as personal property that aids a patient’s treatment.

The technology requires others to help position the cap tightly and evenly on the head. A patient wears the caps for 8 hours during each round of chemotherapy, rotating the gel packs throughout the 8 hours so her head stays freezing. Administering the caps begins hours before infusion and continues hours after, possibly extending the infusion process, especially in American infusion centers that are ill equipped to handle the extra time and effort involved. Downsides to this technology are the physical pain (i.e., migraines or feelings of hypothermia) and the cost, as it is not covered by health

insurance in the United States and averages around four thousand dollars (www.rapunzelproject.org, 2015).

The inconvenience of scalp cooling technology is apparent. Upon observing the process of administering cold caps during infusion, I am confident arguing from an organizational perspective, the technology and the patient using it slow down the efficiency of the clinic because it requires accommodation to which most staff are not used to adhering. This can create tension among patients, loved ones, and hospital staff. It adds discomfort to an already painful and time consuming process.

From a critical communication perspective, I wonder to what degree scalp cooling would be perceived as a personal and organizational inconvenience if baldness was a socially stigmatized side effect for men and women instead of only women. Would American health insurance be more likely to consider reclassifying scalp cooling as an acceptable form of side effect management? As stated earlier, wigs are a non-technical technology, yet they are also gendered in a similar manner to that of scalp cooling and cold caps. If CIA signaled illness across sexes, (Freedman, 1994) cold caps might be a more popular topic of discussion, or wigs at the very least.

## **Stigma**

The discomfort experienced by those who are stigmatized and those who perform the stigmatizing is described by Goffman (1963) as “an infinite regress of mutual consideration” (p. 18), where a patient knows others are aware of her altered appearance and others sense the patient is conscious of their awareness. Keeping this regression of perception in mind, it is critical to generate empirical data examining the degree to which alopecia-related stigmatization, or the perception of being stigmatized, takes place



throughout the course of treatment and how this informs how patients perceive their quality-of-life throughout the course of chemotherapy.

Each person possesses at least one characteristic that sets him/her apart from the social norm or what is considered “normal” (Tyler, 1974, p. ix), yet the ways in which atypical traits are accepted or rejected is highly subjective and imbalanced. The construction and maintenance of what might or might not constitute a normative appearance, behavior, or value is historically contingent. For example, Warren’s (1980) research in sexuality studies demonstrates how stigmatization is historically contingent. Warren argues more attention needs to be paid to “the social roots of homosexuality in a society that stigmatizes homosexuals...and affects the adoption of a homosexual or lesbian identity and the formation of gay communities” (Warren, 1980, p. 123).

Those who read Warren’s (1980) work might recognize the progress American society has made regarding gay right/human rights. Even so, adjusting social norms is a slow process. The historical and political struggle to become a more inclusive society persists, and identifying as gay or lesbian in American society continues to involve issues of stigma, especially when considering sexualities in addition to gay or lesbian that challenge heteronormativity (e.g., bisexuality or the sexuality of those identifying as transgender). Grounded in issues of health, uncertainty, social exchange, and perceptions of the self, Goffman’s (1963) work on stigma gives theoretical and practical grounding to argue individual experience is deeply embedded in the social sphere, which often works to solidify popular opinion and maintain cultural norms.

Stigmatization is learned. It is an active practice and is often reinforced over time by members of society as well as social institutions. Those who stigmatize are often supported

by the social majority's disapproval, frequently positioning those who are stigmatized in a reactive role (Goffman, 1963). The everyday nature of stigmatization and its social acceptability demonstrates how it is a communicative process involving negotiation among individuals and the social systems in which they interact (Goffman, 1963; Warren, 1980). In the context of research on women's health and side effect management, hair loss can be conceptualized as stigmatization because American society often interprets a woman's bald head as a sign of having cancer, a stigmatized condition (Rosman, 2007).

The complex relationship between managing one's appearance and experiencing cancer is apparent when considering how the standards of "looking good" are culturally embedded (Hansen, 2007). Don DeLillo (1985), an American novelist known for his critiques of the public sphere, demonstrates the intimate relationship between illness and aesthetics, arguing "we seem to believe it is possible to ward off death by following rules of good grooming." It is difficult to "properly groom" a body undergoing the intensity of chemotherapy, where drugs such as paclitaxel (taxol) cause alopecia, scalp irritation, nausea and vomiting, fatigue, loss of appetite, diarrhea or constipation, swelling, mouth sores, joint pain, and neuropathy, among others (oncolink.org, 2017).

In the context of cancer, the notion of warding off death has been appropriated by a discourse of battling disease (Lerner, 2004). It is the patient versus the cancer, though both are stuck sharing the same body. How then do patients describe their hair loss? Do they suggest it is part of a "battle" with cancer or is the experience articulated within a different framework? Juxtaposing the standards of "good grooming" with the reality of chemotherapy and its side effects, do patients view their baldness as a signal of their attempt to ward off death? Do ovarian and uterine cancer patients perceive their peers as

using socially constructed standards of “good grooming” as a discursive frame to negotiate and make sense of one another’s roles during social interactions (see Goffman, 1963)?

Chemotherapy-induced alopecia involves personal and social “confrontation with the lethal nature of cancer” (Rosman, 2004, p. 333). Goffman (1963) describes society’s classifications of non-normative physical features like chemotherapy-induced alopecia as “an abomination of the body” because it directly relates to a physical appearance that signals specific meaning to others and conveys illness and potentially dying. The “specific meaning” signaled by a bald head is gendered, which is why hair loss during chemotherapy is a women’s health issue. Considering the social and psychological significance of public opinion, is *appearing* as though you have cancer a concern that exists on a similar level of importance as the disease itself? Does appearing as though you have cancer and actually having cancer issues worth separating or are they inextricable? This is a question that has not been adequately addressed in the literature and warrants further examination, which is why interview participants will be asked if appearing sick makes a difference to their actual health status or how they perceive their quality-of-life.

The degree of control patients have over disclosing a non-normative characteristic matters in the sense that those who can conceal their stigmatizing condition from the public eye can exert some autonomy over when and how confrontation with one’s stigma might occur (Goffman, 1963). Disclosing your health status to others might distress a patient at risk of being stigmatized, especially when a stigma can lead to outright rejection rather than acceptance. In contrast, patients may want to maintain some degree of uncertainty about their health status to keep the stigma of disease from “looming large” (Goffman, 1963)

during social interactions.

Rosman's (2004) research on hair loss among women with breast or lung cancer is one of the only studies of chemotherapy-induced alopecia that incorporates stigma. According to Rosman (2004), women with cancer who are bald experience stigma, and as a result, they often use wigs to maintain uncertainty about their health status during social interactions. The decisions accompanying hair loss, including how, why, and when to wear wigs were perceived by Rosman's (2004) participants as a problem greater than fatigue and pain because of the impact baldness had on social relationships, suggesting stigmatization – or the perception of stigmatization– is an issue of concern during chemotherapy.

Conceptualizing wigs as a form of prosthesis used to assimilate or cover (Yoshino, 2006) a part of the body that runs the risk of being stigmatized suggests wearing head scarves or turbans is different than wearing wigs because they do not cover the stigma of having cancer in the same ways. In their study of hair loss among Turkish women cancer patients, Erol, Can, and Aydiner (2012) position head covering as part of the alopecia process, arguing studies examining head coverings should separate wearing wigs from wearing headscarves because patients perceive them as different acts. Turkey and America vary in degrees of secularism, and while the connection among religious head coverings and decision-making practices during chemotherapy-induced alopecia are not discussed at length in this dissertation or in Erol et al.'s (2012) article, their work demonstrates a need for specificity when patients are asked about their preferences.

**Stigma in the context of gender and illness.** Hair loss is an active process played out on a public stage, often involving active decision-making concerning whether to cover one's head and how to go about doing so if you do. The individual and social elements of

hair loss and subsequent decision-making position covering as a practice connected to identity politics (Yoshino, 2006). Inspired by Yoshino (2006), Galman (2013) examines head covering in relation to religious affiliation and social assimilation. Galman (2013) argues wearing a wig is an act of covering, while wearing a turban or headscarf is an act of uncovering “in the sense that [women] are choosing to actively resist the pressure to cover in the sense of choosing to nonconform” (p. 423). Since headscarves do not conceal a stigmatizing health status in the same way a wig might, wearing a headscarf suggests an active decision to “uncover” (Galman, 2013) or reveal one’s diagnosis to the public sphere.

More research is needed to address the decision-making involved in wearing scarves, turbans, and wigs. Side-effect management studies would benefit from an approach that understands communication as central to decision-making. There remains a lack of attention toward the relational elements of side-effects, such as how hair loss impacts a patient’s ability to perform certain social roles (e.g., grandmother, mother, career woman) as well as how patients communicate with strangers, loved ones/acquaintances, and fellow patients/survivors during and after CIA.

Following Price Herndl’s (1993) warning against blurring distinctions within a patient population of interest, it is important to recognize not all female cancer patients are stigmatized to the same degree, nor are all females equally concerned about appearing as though they have cancer or the stigma which this carries. Stigmatization is a socially constructed process that can, at times, be contested or renegotiated. The emotional toll of functioning in accord with social norms to which you do not fit is not an equally distributed, shared experience among all females with cancer. Even so, as Price Herndl (1993) explains, “while we are not all marked by physical invalidism, we are all marked

by cultural invalidity; we may not be invalid women, but we do have a certain solidarity with them” (p. 3). Just as cancer is known as “the great equalizer,” stigmatization may be perceived as a great differentiator, thus we all have a stake in the process regardless of health status.

The discourse of cancer and hair loss is gendered not only on a social level in the public sphere (Lorde, 2009) but also on an organizational level within healthcare institutions. A key example of this is the “Look good, feel better” program put forth by the American Cancer Society and sponsored by cosmetic companies like Proctor & Gamble (lookgoodfeelbetter.org, 2012). “Look good, feel better” (LGFB) targets female cancer patients, acting as a discursive frame to enforce the connection between self-confidence, appearance, and perhaps what it looks like to perform a “good cancer patient” or a “woman with cancer.” Feminist scholarship examining the social and political implications of performing patient and performing gender (Gubar, Oct. 9, 2014; Hooper, 1994; King, 2006; Korsmeyer, 2004; Lorde, 2009; Price Herndl, 1993) should be understood as foundational conceptual frames through which health communication scholars can best analyze how patients view and use the LGFB program.

The American Cancer Society’s LGFB Program is among the primary sources of support –if not the only source of support –to which many oncologists refer patients for help in managing hair loss. This is troubling because the program’s focus on cosmetics may be too narrow for patients who are concerned with seeking support related to managing a change in appearance known for being a side effect of cancer treatment. Social or familial pressure to “look less like a cancer patient” by using cosmetics is different than clinicians and other healthcare providers using LGFB as a primary referral

for emotional support and information, but interview participants might not perceive this difference as meaningful (which is why participants will be asked how they view the LGFB Program and their opinion of the motto, “look good, feel better”).

**Stigma and the feminine fighter.** Medical historical narratives of the 21<sup>st</sup> century propagate cancer as a battle for survival (Lerner, 2004). Fulfilling the warrior role leaves little room for women with cancer to disclose their concerns for a changing aesthetic. The grand narrative of battling cancer is further complicated when considering the rules and expectations for performing gender through physical appearance (see Butler, 1993) as well as the limited patience American society has for those who are ill (Ehrenreich, 2009).

Regulating one’s physical appearance in an attempt to manage the emotional well being of others is often fueled by gendered expectations. It is a form of what Hochschild’s (1989) refers to as emotional labor. The warrior-based discourse our society employs to describe the expectations for how a patient should manage her symptoms and cope with disease exists in contrast with standardized social practices of femininity (Butler, 1993). Consider the following contradiction: an ovarian cancer patient is expected to continue her gendered performance of “woman” and appear “womanly” while also communicating her willingness to “fight for survival” and “battle” her disease.

There is a wealth of research on the social construction of the warrior/fighter trope to examine how women are expected to frame their experience (i.e., battle) with cancer (Ehrenreich, 2009; King, 2006; Lerner, 2004; Sulik, 2011). From a Weberian (1930) perspective, the spirit of American survivorship values the individual’s struggle of

battling cancer as a successful venture in itself regardless of the outcome. Aware of the social implications for what metaphors are appropriate to describe cancer (i.e., as a battle one fights), research should examine how these expectations might undermine a patient's ability to communicate concerns related to alopecia that may not parallel the "fighter" frame.

The perspectives of female patients who have little to no concern for losing their hair should also be included when examining social expectations of appearing "womanly" while simultaneously performing "fighter" during chemotherapy. Understanding the pressure to fulfill multiple roles and function in society might influence a patient's quality-of-life. Likewise, how a patient describes her quality-of-life before and during cancer treatment might impact how she interacts in public and private spaces. Indeed, they may not be separate issues.

### **Quality-of-life**

The public nature of hair loss combined with American society's limited acceptance of difference in women's appearances (see Lorde, 2009) might affect ovarian and uterine cancer patients' quality-of-life (QoL) during chemotherapy, especially if QoL is defined in the context of relationships. For instance, if a patient's QoL is partially defined by time she spends with her grandchildren but they communicate hesitation and are physically distant when she is bald, there may be a strong connection between alopecia and a lower QoL. The relational aspects of this example are rarely examined in this area of research, thus there are few studies to reference (see Freedman, 1994; Power & Condon, 2008). How the individual experience of alopecia is embedded within the context of relationships is an issue needing further examination. Incorporating quality-



of-life studies into research on CIA gives us a more thorough frame through which we can conceptualize the communicative aspects of alopecia.

Quality-of-life during cancer treatment has been a research interest for healthcare practitioners and organizations since the late twentieth century (see Aaronson et al., 1993; Osoba, 1994). As discussed in the introduction, cost and delivery of care as well as the quality of care are among the key concerns of 21<sup>st</sup> century medicine (Gupta et al., 2013; Robinson et al., 2012). The concept of quality is subjective, making it more difficult to measure than duration, speed, or cost of care. Gupta et al. (2013) describe the concept of quality-of-life as a multidimensional construct including physical, social, psychological, and functional domains of life. The World Health Organization (2002) defines quality-of-life as “individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHOQOL, 2002, p.1).

While quality-of-life (QoL) is heavily dependent on individual perceptions and cultural values, the assessment tools and strategies related to measuring QoL are usually standardized and quantitative, testing long and short-term effects of health status and functional ability using a series of closed questions with response options in the form of numbered scales. For example, the World Health Organization (WHO) developed an expansive 132-question survey with 32 questions targeting issues of spirituality, religiousness, and personal beliefs (SRPB) and 100 questions testing multiple variables such as the ability to work, satisfaction levels related to mobility, sexual practices and health status as well as energy levels, amount of sleep and fatigue, and to what degree a patient “accepts her/his appearance” (WHOQOL, 2002).

QoL surveys test different variables, suggesting there is no absolute standard of measurement (see Osoba, 1994). For instance, the WHO's survey tests for issues of appearance and body image, yet a 30-question quality-of-life questionnaire (QLQ-C30) developed by the European Organization for Research and Treatment of Cancer (EORTC) does not include any questions related to managing appearance. The EORTC's QoL survey is mentioned in the introduction of this dissertation because it is designed specifically for cancer patients. The popularity of using the EORTC to measure cancer patients' QoL suggests the issue of managing appearance and the issue of having cancer are seen by those who use the EORTC as unrelated or unimportant. Excluding variables related to appearance-management suggests a lack of appreciation for how visible side effects such as hair loss can impact a patient's quality-of-life during cancer treatment.

QoL assessments often use Likert-type scales, such as a 5 point scale with 1 representing "not at all" or "very dissatisfied" and 5 representing "extremely," "completely," or "extremely satisfied." For example, Question F7.1 in the WHOQOL asks (in reference to the last two weeks), "Are you able to accept your bodily appearance?" with the following choices: 1="not at all" 2="a little" 3="moderately" 4="mostly" 5="completely" (p. 10). Similarly, question F7.4 asks, "how satisfied are you with the way your body looks?" 1="very dissatisfied" 2="dissatisfied" 3="neither satisfied nor dissatisfied" 4="satisfied" 5="very satisfied" (p. 13). There are two more questions directly addressing "looks" (F7.2, p. 6) and "appearance" (F7.3, p. 6).

To the best of my knowledge, there are no quality-of-life surveys specifically devoted to an examination of chemotherapy-induced alopecia. Using the WHO's survey tool or similar QoL survey tools (Osoba, 1994) as part of a project examining

chemotherapy-induced alopecia may provide a baseline assessment of patients' values and attitudes, but it does not provide the opportunity for depth nor does it provide enough breadth to stand on its own in the context of an ongoing experience like hair loss and the emotions associated with it.

The argument for more in-depth quality-of-life research addressing the “why” and “how” associated with assigning numbers to feelings has been a problem of interest for decades (e.g., Gallagher, 1997; Wagner & Gorely, 1979). Since the early 2000's, there has been a more focused effort to generate more qualitative, interview-based research focusing on chemotherapy-induced alopecia as it relates to quality-of-life among female patients (Can et al., 2012; Erol et al., 2012; Firth et al., 2007; Jayde et al., 2013). QoL research on chemotherapy-induced alopecia is lacking in its attention to gender and the gendered dynamics of the self and society that may be in play during chemotherapy and may influence the way a patient conceptualizes her quality-of-life and the ways her changing appearance impacts it. Incorporating issues of gender into QoL studies is one way communication scholarship can contribute to the existing body of knowledge, especially as it relates to women's health.

From a qualitative research perspective, the lack of an absolute standard for evaluating or defining quality-of-life suggests there is room for and openness toward developing new evaluation strategies and interpretations. To advance the process of defining and describing quality-of-life, the field should look to qualitative scholarship produced by landmark scholars such as Charon (2004) who work to advance the voices of the participants through performative communication acts such as descriptive writing.

Influenced by this link of thinking, this dissertation's interview process will ask patients to respond in writing to the following prompt: "to me, quality-of-life means..."

Epistemologically, the patient's voice supersedes existing definitions, allowing QoL research to move forward as comparisons and contrasts can be made among institutional definitions and those of the patients'. Whether or not interview participants mention hair loss or other side effects of chemotherapy is of interest and may further complicate the argument for connecting quality-of-life with alopecia.

### **Rationale: Situating the problem of interest**

Situated in the field of health communication, this project's major area of emphasis is in health communication and minor areas are in qualitative inquiry, quality-of-life studies, women's health, and side effect management. An analysis of patient experience calls for a research method rooted in the epistemology of interpretive claims. The nature of the research questions and the method of semi-structured, compassionate interviewing (Ellis & Patti, 2014) allows for a discursive space of openness, which is a more natural fit with how we share experiences (Frank, 2013) and how we articulate our health status to others (Roscoe, Eisenberg, & Forde, 2016).

This research functions with an epistemological understanding that there is no single starting point by which to measure patient experience nor is it possible to have a complete understanding. Patients' experiences are already being crafted, told, and retold before interviewing takes place and will continue to be storied after the interviewing is complete (Bochner, 2014; Charon, 2004; Frank, 2013; Roscoe et al., 2016). This does not negate the opportunity to generate data that can improve the field.

## **Conclusion**

The majority of research on chemotherapy-induced alopecia has a clinical focus examining the psychosocial effects of alopecia or measuring its association with quality-of-life through survey tools that pay little attention to hair loss. It is critical to recognize the subjective nature of quality-of-life and identify the need for a methodological approach that investigates how perspectives change over time. This project will strengthen the field's understanding of the subtle differences as well as the patterns of communication among ovarian and uterine cancer patients' perspectives of hair loss and its impact on quality-of-life during chemotherapy.

## CHAPTER THREE:

### METHOD

*“Instead of viewing these events [of illness and loss] as tangential interruptions [during interviews], we treated them as opportunities to be present...in being compassionate listeners, we let the conversations go where they needed...and understood that losses accumulate...”* (Ellis & Patti, 2014, p. 392).

*“After many years in the world of medicine and health care...I have come to think that it is not so much autonomy that lies at the basis of our lives as moral creatures...It is rather...the responsibility that each of us bears to respect the autonomy, the self and the life and humanity of the other. The one who is profoundly vulnerable thanks to illness...at whatever stage or condition of life that self or person may be and in appreciation of all its significant and subtle implications”* (Zaner, 2004, p. xiii).

#### **Introduction**

The choice of research method is based on questions the researcher is interested in examining. The link between the question and method is often described in most published research in a clear and concise fashion, but what about the steps beforehand? In addition to reviewing extant literature, what prompts the research questions and method, and how does a research project materialize? To provide insight into the development process of this research project, I share the happenings of two especially momentous meetings. There are four years worth of intellectually stimulating conversations with my major professor I could reference as helping inform my methodological approach, but I am sharing one from March of 2014 to historically situate the narrative. The second meeting is between Dr. Mian Shahzad and me and takes place

in August of 2015. I share these specific conversations and two life-changing mentors because they mark specific moments of progress in my dissertation journey toward helping improve the quality of communication in women's oncology.

Beyond the intention of detailing my development process, the following narrative exemplifies "behind the curtain" dialogue between student and professor. In the larger sense, a "behind the curtain" account of my project and method parallels the overall function of this dissertation, which is to describe and interpret the all too often overlooked, "behind the curtain" problem of experiencing chemotherapy-induced alopecia (CIA). In physical form, CIA is not a "behind the curtain" issue; rather it is embodied on public display, what Goffman refers to as "front stage," visible communication (Goffman, 1956). Even so, the social stigma of being a bald woman (i.e., cancer patient) suggests this is often experienced behind the curtains, thus it makes sense to perform compassionate, in-depth interviews devoted to unpacking patients' perspectives of CIA and the connecting issues that inform their ability to manage "looking like a cancer patient." At the conclusion of the following narrative, the research method is described, including how and when data were collected, participant inclusion criteria along with approvals from the University of South Florida's Institutional Review Board (IRB) and H. Lee Moffitt Cancer Center's Scientific Review Committee (SRC). Interview procedures are discussed along with a description of how codes were developed and applied to the thematic analysis.

#### **Narrating method: A narrative account of the methodological process**

Like many progressive faculty members, Lori goes by her first name instead of Dr. Roscoe. Lori and I regularly schedule "check-in" meetings, and this one is to discuss

potential sites of fieldwork for Chaim Noy's ethnography class I am taking in the spring semester of 2014.

"I keep coming back to Kang's (2010) ethnography."

"Why?" Lori asks. "What makes it interesting?"

"Well, she uses Hochschild's (1979) theory of emotional labor to examine service work in a Korean-owned nail salon," I respond with certainty.

"Yes, but what makes it interesting? Why is her work useful? What does it contribute?"

"Ok, I understand. For starters, it's interdisciplinary. Kang (2010) is a Women's Studies and Asian Studies scholar, and her work is not bound by the specificities of one field. An MBA student could read her work (2010) and better understand labor relations on a macro, meso, and micro level. For me, the work contributes more to method than theory. The way she conducted interviews is highly interpersonal, like a conversation with purpose. The book is not a methods piece, so I find work like Ellis and Patti's (2014) more applicable to an argument for the best practices of interviewing. Regardless, Kang's (2010) work lit a fire in me!"

I'm speaking more quickly than I'd like. I'm excited to discuss method. I take a deep breath, then say, "As I'm thinking of the dissertation, I move closer toward interviewing as the primary method and farther away from more classic ethnography, yet I'd like to maintain a similar methodological ethic as Kang. She positions participants in the center of the analysis, which is what we do in this department! It's what you do! It's what Kang does! I want to contribute in the same vein."

"Good! This is good!" Lori smiles. She can tell I have more to share.



“I’m fascinated by gendered spaces, Lori, and gendered aesthetic practices like nail care or hair care. Nail salons are absolutely gendered, but does that make it an issue of women’s health? What about gendered spaces of healthcare? What would a study like that look like?”

“What you’re saying reminds me of a former student who wrote a fabulous class paper on Moffitt’s hair salon. Do you know they have a hair salon?”

“No, I didn’t.”

“Yes they do! Hold on, I think I have a copy of her paper in my files.”

Lori pulls open the bottom drawer of her filing cabinet. “I know I have it somewhere. Her name is Jennifer Pickman (n.d.). She volunteered in the salon and was also a client. She had cancer and passed away years ago. Oh she wrote the best piece on waterskiing in a wig! The one I want to share with you though...here it is!”

“Another Thursday hair appointment,” I read aloud. “What a great title.”

“Jennifer is how I know about the salon. The paper is short in length and has a strong first person focus because she’s writing from the perspective of a patient. I’d expect you won’t find a lot of overlap with your methodological interests, but her work will serve as inspiration.”

It certainly will! This is excellent,” I say while flipping through the pages.

“Consider checking out Moffitt’s salon and report back!” Lori says with enthusiasm. “It seems like a good blend of women’s health and gendered aesthetics, but you won’t know until you observe.”

The day after our meeting, I am visiting Magnolias, Moffitt’s hair salon, asking for permission to perform preliminary observation for an ethnography class at USF.

Before then, I have not been inside Moffitt. It's less than half a mile from USF's Department of Communication, but driving past it is the closest I have come.

During my first visit, I speak with the stylist about Jennifer's paper, explaining she wrote about her experience as a client and a volunteer in the salon, and it inspired me to come here. The senior stylist remembers Jennifer, saying she was a supportive volunteer. "I needed help keeping track of the finances, and she was really good with that. She'd help me stay organized." The stylist laughs, saying, "Jennifer was always taking notes. She said it was for a class. It makes more sense now. What's she doing?"

I share the sad news of Jennifer's death. The stylist reacts in a way that reflects her decades of experience working with cancer patients. "That's how it is –taken too soon and too young. So many of these women are on their way out...maybe her stuff can come back to life through you." I sigh then say, "I hope so. I hope she'd be proud of me and us, and what's going on here...I know she'd be proud of you and the decades of work you've done here. I still have a lot to prove, but I'll get there." She replies, "of course you will, Mare-a-deeth," saying my name in an accent that is not hers. We both laugh.

The salon door opens and we stop laughing. "Hi, how can I help you?" she asks in a professional tone. "We're here for a wig," the patient says. After getting her informed consent for observation and an interview, I learn she and the woman accompanying her are lifelong friends who met decades ago while working as flight attendants. She retired a few years ago and carries a "from hello...to bye-bye" card her colleagues made. She gives me the card to remember her, and I treasure it. Still having a full head of hair, she insists it is thinning and explains her reason for visiting. "I'm preparing to lose my hair...oh, it's so important. Being a flight attendant for 20 years, I've always taken my

appearance seriously...it's about how others see you, how I see myself...or how I think others see me...I'm not sure what's the difference between those things. They all overlap to me." She continues, "I want to look feminine at any age because I am feminine and I want people to see me with hair...I've always gotten compliments on my hair."

(Interviews from the salon are not part of data under analysis from this dissertation, yet I am sharing a part of this patient's description of the importance of wearing a wig to give insight into how this project evolved).

I visualize the retired flight attendant and her friend sitting in the exam room. What will they discuss while waiting for the oncologist? Will her list of concerns and questions for the doctor have "my hair" on it? Why or why not? Because it is understood as inevitable, is it equated to unimportant? Would a she wear a wig to the appointment? Why? Because hair loss is a side effect of a life saving/life prolonging treatment, is it trivial? If not, does its degree of importance change as chemotherapy continues? With the limited time she has with the doctor, maybe alopecia does not make it into to conversation. Does she speak with a nurse? What about speaking with me outside the salon? What would an in-clinic consent process and interview look like? If I could, I would ask her similar questions to the ones I do in the salon, like "how do your opinions about hair loss change over time or have they stayed the same?"

This particular patient is extremely concerned with the loss of her hair, while others are not. Yet they share the common thread of visiting the salon, where the focus is on managing appearance. How do patients communicate their experience of hair loss in the clinical context, a space less focused on aesthetics? What about phone interviews?

That could contextualize their perspectives further, where they are sharing the clinical and everyday lived experience.

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Over the spring and summer of 2014, preliminary observations yielded enough intrigue to apply for IRB and SRC approval. The IRB and SRC are two different review boards with separate policies and operating systems. University of South Florida's Institutional Review Board (IRB) grants approval after Moffitt Cancer Center's Scientific Review Committee (SRC) issues approval, making it extraordinarily difficult for a non-Moffitt employee, student-researcher of the humanities to conduct research within their institution. It was rare to come across other students, but those who I met were medical students. The process of IRB and SRC approval is explained in more detail later in this chapter.

For the sake of this narrative, it is important to know I conducted ethnographic observation and interviews in the salon from September 2015 to March 2016. This salon is different than most because its only clients are cancer patients and it exists within a major cancer research institute. Over time, I observed and participated in a variety of interaction among patients, caregivers, and stylists that led me to wonder if and how hair loss was discussed in the clinical context. Interviews and observational data that took place in the salon are not analyzed in this dissertation because they extend beyond the focus on this project. The research provided rich information and influenced how the development of the research questions and the interview guide. Time spent in the salon provided context for interpreting my findings.

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The following is an excerpt from an e-mail I sent Lori in late July 2015:

“Hi Lori, I hope you’re doing well. Writing to share good news. I have a meeting August 3<sup>rd</sup> with Dr. Mian Shahzad. He’s a gyn oncologist at Moffitt. Thanks to some ob/gyn networking, he’s agreed to a meeting where we’ll discuss research opportunities. I’m hoping he’ll be open to the idea of granting access to his clinic to do research specific to hair loss, but at this point, I’m just excited to have his advice on how to address the issue from a clinical perspective. Hooray!”

She replies one hour later: “This is excellent M! Let me know how it goes –Lori”

The August 3, 2015 meeting between Mian and me changed the direction of this dissertation.

“I looked over your C.V. before our meeting. It’s impressive,” Mian says as he gestures toward the chair. There are a few chair options in his office, so I hover for a moment weighing my options.

“Take a seat here if you’d like. It was a gift. It’s my favorite one.”

“It’s red! How unique.”

We speak casually about the ways communication studies can inform the ways healthcare is practiced and we discuss the specifics of side-effect management. I ask his opinion on chemotherapy-induced alopecia and its impact on his patients.

“Oh yes, alopecia can have a significant impact on my patients. For some of them, it’s very distressing. My dissertation was on stress and how it can increase tumor growth, so I try to speak with my patients about ways they can manage their stress during chemotherapy.”

I share a synopsis of my experience in Moffitt's hair salon, including how I witnessed many head shaves and observed the different ways patients reacted to their sudden change in appearance. We talk about head coverings and womanliness. Given my academic training and previous research in hospitals, he is assured I understand the subjective nature of managing alopecia. Head shaves happen outside the clinic, so I share some detail though I am confident he has already reflected on it or he would not have agreed to our meeting.

“Some women bring support systems while others march in alone saying, ‘let’s get this over with. I don’t have much time!’ Some are too sick to leave their room, so the stylist goes to them. Most who get their shave and try on wigs during the same appointment tend to be more comfortable by the time they walk out than those who leave bald.

I remember when a woman brought friends from work and it was anything but supportive. I’ve spent enough time in the salon to recognize nonverbals signaling hesitancy, and this woman was extremely anxious. Once the clippers turned on, the patient started shaking. Her colleagues were unable to handle it. The salon is feminine – it has pink everywhere –but the tone isn’t celebratory. I think these women expected it to be, and they hadn’t thought through the severity of the situation. Tears were streaming down her face, and she didn’t say a word. The friend responded to her crying saying, ‘Oh, you’re going to be fine...this isn’t so bad.’ And another said, ‘oh, you look great. I could never pull this off!’ And someone said, ‘Yes, girl, you look just as beautiful! Who knew! The patient was speechless. The friends hovered and cross-talked about how good

the patient looked, all the while excluding her. It was her moment. Her illness. Yet there was no room for her to speak.”

“I’m sorry to hear this. Support is sometimes complicated. I see this in the clinic. Some family and friends are there more for themselves than for the patient. Let’s talk about wigs. Not all patients wear wigs or want to. If there was a clear connection saying if you wear a wig, it will help you cope with your alopecia, then we could simply recommend wigs to patients and they’d have a stronger sense of self.”

“Yes, but it is more complicated than that,” I say.

“Exactly. Correlations might exist but it seems causations do not...” he wonders aloud, “What are the factors that make this so complicated?”

We speak about the decisions patients faced and how they interpret the stigma of “looking like a cancer patient” in a society with certain ideas of womanliness.

“I have a clear answer to why it’d be useful to work with ovarian and uterine cancer patients to study alopecia, but I’d rather hear it from you. Why these patients, Meredith?”

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I expected Mian to ask this question. It’s an important one. Because of the hair salon ethnography, I met women (and some men) with different forms of cancer and various degrees of severity related to their hair loss and stage of disease. Seeking the opportunity to work with gynecologic cancer patients was sparked by the salon space. Once my interest was set in motion, I read extant literature on alopecia and made deeper connections between embodied experience and social stigma.

The gendered aesthetic of the salon is highly feminine. In addition to the two head shaving stations and a wall of wigs, there are shelves of pink hats, nail polish, and jewelry. King's (2006) argument about pink washing certainty applies to the salon culture. Her argument is more focused on the politics of philanthropy, but those issues permeate the space. The interactions taking place within the salon are partially influenced by the shelves of items related to "ribbon culture" (see King, 2006). An issue needing critical examination but beyond the scope of this project was the client demographic, including how and why women grossly outnumbered men.

I wrote a conference paper on the gendered implications of the salon space, and while a full examination is beyond the scope of this dissertation, the argument challenged the hospital's decision to locate a women's-centered space in the basement far away from any clinic a patient regularly visits. Clients of the salon often struggled to find the salon and regularly complained about its small size, and rightly so because it was approximately 400 square feet yet expected to serve all of Moffitt's clientele. An interview participant said going to the salon made her feel like she was being transported to the 1950s. I argued the healthcare organization should disregard for side effect management specific to women and needed to reevaluate its standards.

Months into fieldwork, I began wondering how the communication about hair loss in a gendered, women-centered clinical space would compare to the communication I was observing in the hair salon. In the world of cancer care, what clinical space is more women-centered than a gynecologic oncology clinic? My research interests shifted to communication in the clinic about hair loss, a not-so-clinical side effect of chemotherapy. As I reviewed existing studies on the subject, I better recognized the complexity of the



problem. Some women visiting the salons for wigs or a head shave were in stage I of their disease. As an outsider, each patient's account of her cancer was heart wrenching. The stage IV ovarian cancer patient I met during a wig fitting whose "silent killer" resulted in "everything inside being taken out" helped me better understand the particularities of this patient population. I wanted to learn how the side effect of hair loss was communicated among gynecologic oncology patients, and I needed Dr. Shahzad's guidance.

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Responding to Dr. Shahzad's question regarding why this patient population, I say, "Thank you for asking. The patients you treat are seriously ill, so their perspective on a side effect some might deem trivial is highly valuable because they're in an extreme state of managing their disease. These are significant surgeries, and so is the chemotherapy and radiation that's involved. We're going to the top of the mountain here. If your patient population perceives alopecia as a top concern, what does that suggest about the severity of the experience? It says a lot. It says this warrants in-depth examination. Furthermore, ovarian and uterine cancer patients endure surgeries removing anatomy specific to their sex. Managing internal and external losses of parts of the body that are gendered might intensify the embodied experience of alopecia."

"This is an interesting dissertation topic, Meredith. It needs ironing out. Your passion for the subject is clear, and I see the potential of this research. Let's schedule a meeting where you present your proposed research to Dr. Roscoe and me then we will narrow the scope and have you present to our tumor board. I predict they'll also be supportive of this project because it can benefit our patients."

“Outstanding, Dr. Shahzad! Thank you! I have been reading literature on the subject and there seems to be three main issues that are lacking. First, this is a research problem that should be examined using a longitudinal approach so we establish a more thorough understanding of the problem. What if a patient shares competing views from her first and second interviews? It’ll also be useful to see how patients elaborate on their experience since time is such a high commodity when you’re sick. Secondly, alopecia should be conceptualized as an issue of communication because it is personal as well as socially constructed. Thirdly, I suggest a qualitative method of data collection using interviewing. The ethnography of Moffitt’s hair salon gave me a deeper understanding of individualized patient care in a nontraditional space. Alopecia is a gendered side effect. That work will inform how I conceptualize the clinic and how I conduct interviews.

“So what’s the next step?” he asks.

“The next step is to submit an amendment to the protocol approved by the IRB and SRC.”

“How long do you think that will take? A week?” he asks with confidence, suggesting his previous studies have been approved in a short timeframe. This is not surprising. He is a physician-researcher. He is an insider who works in teams that share responsibility. I am none of the above. I am a doctoral candidate and student of the humanities and hold little clout with a major cancer center.

“Dr. Shahzad, the IRB and SRC process took a year. This is an amendment, so I’m guessing a month or so.”

“No way! Really? We need to do this faster so you can begin!” he says.

“This isn’t my first time with IRB. I actually like going through the process because it validates the work. I’ve submitted and acquired approval from the IRB on several studies besides this one, and the process was speedy each time. The difficulty is going between two distinct institutions and doing it alone. Moffitt speaks a different language. For example, as the SRC reviews the amended protocol, I’ll go through a check-and-balance system with the manager of Moffitt’s Division of Population Science and a research services administrator to account for what I’m doing and how. This is similar to working with the IRB, which I’ve done numerous times, but it’s different enough to require additional training. It’s a challenge that will set me ahead of the learning curve, but it also means the wheels move more slowly than we’d like.”

“I can’t image approval taking so long, but I hear what you’re saying. A lot of back-and-forth and institutional red tape” he says. “We go about this in teams so the responsibility is shared. The workload is shared.”

“Yes, that’s what I’m doing next time! The context is key here. I was a complete outsider trying to do research in a clinical setting, submitting a protocol to do qualitative research using interpretative methods,” I say.

“It’s not the typical study conducted here. That’s part of what makes it interesting,” he replies.

“I had two meetings with the head of the SRC to discuss ethnography who was candid enough to say, ‘Meredith, I’m just not sure what ethnography is or how it can be done in a hospital setting.’ The meetings had a supportive tone. The fact I made it this far was not an accident. From an axiological perspective, the gatekeepers were intrigued, but our epistemologies were not aligning. We went back and forth for months reframing the

protocol until we reached a consensus. It's certainly prepared me for the grant-funded research process. Before this, I understood the process as more clear-cut where a project was accepted or rejected –revise and resubmit, then revise again and gain approval. This was not the case. This was a negotiation of epistemology, and I was fortunate enough to work with Nina Naas, who works in the Division of Population Science managing projects. We had multiple training sessions. She shepherded me through an opening that barely existed. Without access to the institution, I wouldn't be prepared to ask for your help with access to your patients.”

“Sounds like extensive vetting. But you're in now?” he says with a smile.

“Yes, I'm in! Your institution is extraordinarily protective of its patients and electronic medical records system.”

He nods in agreement, suggesting what I said was obvious. Classified as a “student in health behaviors and outcomes,” I entered the Moffitt system in multiple ways. For example, I entered as if I was a new employee, so I had an off-site drug test, background check, blood test, and vaccinations. I attended an orientation and took a “new employee” quiz online. I also entered the institution as a “research coordinator,” meaning I was trained in HIPPA compliance. The training sessions were a bit amusing because I was the only one doing qualitative research and the only one coordinating alone, so there was a bit of a divide between me and the other folks in the room who were all postdocs conducting projects in the hard sciences.

“Are you ready to use our EMR system, Meredith? Are you familiar with Oncore and how to read PowerChart?”

“I am trained in Oncore and need your help reading charts. To me, they're written in a

different language.”

“That’s fine. We can teach you in-clinic,” he offers.

“Wonderful, thank you. I have an ID badge classifying me as a student with formal access for about two and a half years.” I stop to take a deep breath, realizing my previous description of the SRC process was overkill. The clock reads 10:57 a.m., and we were scheduled to end at 11:00 a.m. I reach for my backpack as a gesture to show I realize it is time to close the conversation.

I follow Dr. Shahzad into the hallway. “Thank you for agreeing to work with me. I’m thrilled you want to study this area of care and hopefully improve the field. You round out a group of rock stars! My dissertation committee already has four tenured faculty, and now an M.D., Ph.D. is joining the think tank! What a range of perspectives! This is going to change everything!” I exclaim.

“Good! Please e-mail to schedule the two presentations dates. I look forward to meeting Dr. Roscoe...Lori Roscoe, studying end-of-life communication?”

“Yes, Lori.”

“This will be good. A lot can be done here. See you soon,” he says.

By November of 2015, the amended protocol and consent forms were approved by Moffitt’s SRC and USF’s IRB. A month before I presented the revised study and its intentions to Lori and Mian. We agreed research on experiencing chemotherapy-induced alopecia should examine issues of quality-of-life and how they are perceived to influence one another. The research questions were revised and I was ready to recruit participants. The next section introduces the research questions. Following, details concerning the

interview process are provided and are followed by a description of coding and thematic analysis.

### **Research Questions**

The epistemology of examining the ways in which patients communicate their experiences and share their perceptions calls for research questions rooted in an interpretative approach. To better understand how ovarian and uterine cancer patients articulate their experiences of chemotherapy-induced alopecia and its connection to quality-of-life, this study poses the following research questions:

**RQ1:** How do ovarian and uterine cancer patients communicate about their experience of alopecia over the course of chemotherapy?

**RQ2:** How does chemotherapy-induced alopecia influence patients' understandings of quality-of-life?

An intended outcome of data collection and analysis is to identify patterns of communication particular to ovarian and uterine cancer patients whose experiences will help the field understand the specifics of hair loss and quality-of-life to better meet the needs of patients who have distress related to chemotherapy-induced alopecia.

### **Interviewing**

**Clearance: Moffitt's SRC and USF's IRB process.** Moffitt's Scientific Review Committee (SRC) and University of South Florida's Institutional Review Board (IRB) approved this study in 2015. Following university and institutional standards, SRC approval was obtained before the protocol was submitted to USF's IRB. The application for both the SRC and the IRB is titled "expanding conceptions of patient care," numbered 18102 for the SRC and 19393 for the IRB. After approval was gained, I submitted an

amendment that was approved by the SRC and IRB in January 2016. I originally had access to the site until July 2016 then submitted for an extension, which granted my access to recruit new patients until September 2016 and access to the site until May 2017. Follow-up interviews extended beyond the recruitment expiration, which was also approved.

**Inclusion criteria.** Participant recruitment spanned October 2016 – September 2016. To qualify for participation patients met the following criteria: 1) 18 years of age or older 2) had a primary diagnosis of ovarian or uterine cancer 3) receiving treatment from Moffitt Cancer Center’s Gynecologic Oncology Clinic 4) about to begin or had just begun chemotherapy 5) currently treated or had been treated with paclitaxel (taxol), the chemotherapy drug that induces hair loss.

**Risks, benefits, and goals.** The objective of this study is to contribute an empirical understanding of how ovarian and uterine cancer patients experience hair loss and managing their appearance during cancer treatment. A primary aim during data collection and analysis is to foster a form of participation that places patient safety and informed consent first. I identify the institution (Moffitt Cancer Center) by name as well as the research site (gynecologic oncology), but I do not identify the names of participants. There are no experimental procedures in this study, so the risk is minimal.

**Describing the research site.** Data collection and informed consent takes place in H. Lee Moffitt Cancer Center & Research Institute’s Gynecologic Oncology Clinic located in Tampa, Florida. Though some patients refer themselves to Moffitt, most are referred by physicians practicing medicine elsewhere. A referral to a gynecologic oncologist might be interpreted as a frightening suggestion because their treatment plans have been

described as the “last chance for hope before death” (personal conversation with a referring gynecologist, Feb., 2016). Moffitt’s gynecologic oncology clinic has two locations. The main clinic is located on the University of South Florida campus and the other is located in Southwest Tampa in the International Plaza (referred to as MIP) adjacent from Tampa’s International Mall. This project took place in the main clinic on the university campus.

There are four gynecologic oncologists in the clinic. Each of the four has a designated day of the week during which she/he treats patients in the main campus clinic. If it is not their main clinic day, physicians are usually performing surgery and making rounds, treating patients at MIP, or addressing issues related to research. Recruitment mainly took place on Wednesdays because that is Dr. Shahzad’s day of the week during which he sees patients.

The clinic exists within the larger organizational structure of Moffitt Cancer Center. As a major medical research center, Moffitt functions within the larger context of the American healthcare system, thus it is important to consider what the data might imply about the individual patient experience as well as the healthcare system at large and the systems of interaction within it. These organizational systems of interaction structure communication within the clinic, thus impacting the process of collecting data.

Structuration theory (Giddens, 1984) and social construction (Berger & Luckmann, 1966) allow for an understanding of how the organization of the clinic guided (at least partially) the ways in which rules, roles, and norms were enacted and negotiated among doctors, patients, providers, and loved ones (Giddens, 1984). Throughout the 210 hours spent collecting data in the clinic, particular attention was paid to how language functioned



in the clinic and during interviews to challenge as well as legitimize social norms that structure patient experiences of alopecia (Berger & Luckmann, 1966). Knowing language constitutes the social process of meaning-making (Bartesaghi & Cissna, 2009; Berger & Luckmann, 1966), it was critical to be mindful of the language patients used during interviews as well as the language I used as an interviewer. Mindful use of language and listening with intent does not equate to interviewing that follows a tightly script. Semi-structured interviews were performed using a tone inspired by Ellis and Patti's (2014) work on compassionate interviewing.

**Semi-structured interviews.** The methodological intention of this study is to collect data that will generate findings to help address the concerns of female patients<sup>1</sup> who are faced with making sense of a changing appearance signaling their health status and how these concerns may change over time. Because of its emphasis on communication and co-construction, semi-structured interviewing is the best way to collect data highlighting the central role of the patient in 21<sup>st</sup> century healthcare.

Existing qualitative research in health communication using semi-structured interviews to examine patient-centered care (see Dean et al., in press; Roscoe et al., 2013) and female cancer patients' experiences of illness (see Anderson, 2014) serve as examples for this methodological approach and guide the decision to use semi-structured interviews for this dissertation. The context of an interview can be critiqued as limited in comparison with more inductive processes such as postcritical ethnography (Noblit et al.'s, 2004) or autoethnography (Adams, Holman Jones & Ellis, 2015; Berry, 2016; Bochner & Ellis, 2016). Previous experiences conducting interviews in teaching

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<sup>1</sup> Refer to Donovan et al., 2014 for more details on research addressing community-specific concerns

hospitals (Clements, 2013) have helped me understand how participants in medical settings often prefer having prompts rather than engaging in impromptu conversations, especially during the initial interview. Purposeful questions can encourage disclosure from both the interviewee and interviewer (Anderson, 2014).

This dissertation intends to further Kleinman's (1988) conceptualization of interviews as acts of telling to suggest interviews have the potential to surpass explaining; rather, becoming acts of sharing (see Ellis & Patti, 2014; Noblit et al., 2004). An interview has the potential to be a dialogic space of becoming, where participants share their biases, emotions, memories, or expectations in ways that can reformulate the topic of conversation (Radley, 1999). Though I hold the position of interpreting the data, it is important to remember where transcriptions originate, which is in the co-construction of dialogue. The flexibility of a semi-structured interview may encourage participants to share in ways I may not expect (Merriam, 2009).

**Intention and tone.** The problem of interest, the time requirement, and participants' health status were approached with sensitivity, and the method of data collection needed to reflect this. Compassionate interviewing (Ellis & Patti, 2014) best fits the overall methodological intention because it frames interviews as collaborations and encourages emotional exchange. Interviewing for this dissertation uses SRC and IRB approved questions to serve as prompts to help stimulate the exchange while unexpected turns in the conversation are expanded upon (refer to Appendix 1 for interview guide).

A close reading of the World Health Organization's (WHO) expansive survey tool used to measure quality-of-life (WHOQOL, 2002) serves as an example of

methodological excess that could lead to patients experiencing participation fatigue, particularly when working with patients who are seriously ill in stages III or IV of their disease. Because scholarship in quality-of-life uses surveys so frequently and because Likert-type scales can provide evidence of a problem and the degree to which it exists, this dissertation incorporated a QoL interview question using a 5-point scale.

Participants were asked to rank their quality-of-life in numerical form with 1 representing the lowest possible QoL and 5 representing the highest. Participants were asked to follow their numbered response with an explanation. The rationale behind the number is often missing in scale-based questions, or the “why” and “how” are measured through a multitude of additional survey questions.

From a qualitative perspective, the number of questions asked matters less than the participant’s degree of disclosure or willingness to provide insight applicable to other variables. For example, question SP3.2 in the WHOQOL (2002) asks, “to what extent do you feel spiritually touched by beauty?” 1= “not at all” 2= “slightly” 3= “moderately” 4= “very” 5= “extremely” (p. 21). This question is more related to aesthetics than appearance, which is less problematic than the fact that this is a confusing question. The phrase, “touched by beauty” seems more like language from an interview where the researcher can provide explanation or an open-ended questionnaire where the participant can write through the confusion. Testing an aesthetics-related variable such as this suggests QoL studies are attempting to examine complex issues but may be missing the mark. The field’s attempt would be bolstered by a qualitative approach with a longitudinal focus, which is the intention of this dissertation research.

**Longitudinal interviewing with compassion.** To the best of my knowledge, longitudinal interviewing within the clinical context is rarely used to examine chemotherapy-induced alopecia (CIA) and quality-of-life. The benefit of using a longitudinal analysis to examine CIA is demonstrated by Munstedt et al.'s (1997) longitudinal study that used surveys to examine self-concept and body image among a patient population similar to those participating in this dissertation project. Research discussed in the literature review shows the importance of collecting data over the course of chemotherapy (Gupta et al., 2013; Munstedt et al., 1997) and highlight how the field continues to lack interview data, leaving sufficient room for empirical research intended to describe, interpret, explain, and better understand.

Analyzing how women articulate the lived experience of chemotherapy-induced alopecia and quality-of-life while confronting a life-threatening disease requires methodological sensitivity. Ellis and Patti (2014) advance the idea of compassionate interviewing as an opening through which interviewer and interviewee work together to generate new insight. The agenda of the interview shifts away from a question-and-answer format and is driven by the need to be mindful during the conversation as opposed to trying to maintain control over the direction of the interview or waiting to receive responses fitting the agenda of the interview. Ellis and Patti's (2014) format encourages adaptability and can create possibilities for intimate dialogue because the emphasis is on emergent communication between participants. Redirecting the attention to the participants instead of the question-and-answer transaction requires a sense of presence, suggesting these interviews can be emotionally strenuous, requiring the

interviewer to have respect for the process and the context in which the patient is participating.

This project's method follows Ellis and Patti's (2014) approach to interviewing and is inspired by their agenda. Their intended outcome to foster long-term friendships with participants differs from the relational intentions of this dissertation. Similar ethics of interviewing are followed, but their call to offer support comparable to that of family and friends (Ellis & Patti, 2014, p. 392) is not answered in this dissertation. I maintain relationships with a few patients, but it is not on the same plane as a supportive partner, friend, or adult child. As transcripts show, most interviews are highly personal and opinionated. At times, they are emotionally productive and discursive. From the perspective of the researcher, all interviews I conducted are revelatory but some were seen as such by the participant.

There are three main reasons why these interviews did not parallel the relational outcomes (i.e., long-term friendships) argued by Ellis and Patti (2014) as fitting the call to conduct compassionate interviewing. First, this approach emerged from longitudinal interviewing between the researcher(s) and one participant. Ellis works for years with Jerry (see pp. 393-398) and Patti with Sal (see pp. 393-403) both of whom are Holocaust survivors. I consented almost thirty women. Fostering truly supportive relationships with all thirty over years to come would be difficult and probably insincere.

At the time of publication, Sal has died, which demonstrates the second point of my argument. Most of my interview participants are not only in the late stages of aging, they are seriously ill, going in and out of the hospital, experiencing waves of pain and other life-altering side effects like depression and anxiety in addition to low mobility.

For example, the difference between the first interview with Patient 9 and the second was remarkable. The first interview lasted two hours. She disclosed fifty-five pages worth of insight into her cancer experience, including hair loss, quality-of-life issues, and more. We laughed a little. At times, she cried. Some chunks of conversation involved me listening to disjointed details about her hobbies and making decisions about who would inherit what. It was compassionate interviewing in action.

The second interview lasted approximately twenty minutes and took place over the phone. Her tone was indicative of the how aggressive her cancer had become. She was dying. “Yes, [my hair’s] growing back, but not fast enough,” she says. “Dr. [name] said I have 6 months to a year to live...I need it to come in faster.” She was anxious, saying she was angry during her last rounds of chemo, and struggled to share a point she wanted to make without it being the same statement as she made only moments ago. This is where a long-term relational outcome does not fit the situation. Some patients are too sick to participate in a way that enriches the interview-interviewee relationship. All shared insight that will benefit how we understand the patient experience, but some were uninterested in deepening our connection. That said, many patients were eager to continue a working relationship and encouraged me to follow-up again for another interview when needed. I provide more detail related to this in the last chapter of this dissertation.

Finally, the choice to recruit and consent patients in a clinical setting suggests a clinical tone might follow throughout the interviewer-interviewee exchange, despite my efforts to enact compassion. Of course, the clinic is a space of compassion, but usually not in the same way Ellis and Patti (2014) share where, for example, Ellis and Gerry

(interviewee) meet for lunch (p. 393). The idea of a clinical communication ethic guiding our conversations is not strongly supported in the transcripts. This is probably because all are aware of my position as a student-researcher at USF studying communication and all the details I cover during informed consent.

On rare occasions, a patient or her adult child would ask me a medical question, and I would remind them I was not a nurse or a doctor and could not answer the question. For example, a patient shared “I’m going to ask Dr. Shahzad about my legs. I have so much pain in my thighs and they get puffy. What do you think?” I replied, “well I don’t know, I’m not a doctor. Asking Dr. Shahzad sounds like a good idea. Puffy thighs and leg pain sounds horrible, though. Is that one of your top concerning side-effects right now?” Almost all participants were almost always clear on my position as a student-researcher, and I was trained by a member of Moffitt’s Division of Population Sciences on how to confirm consent upon interviewing (i.e., remind patient of the study’s intention, her voluntary role in it, and my position) then subsequently observed to assure I was following appropriate informed consent procedure. There were a few instances when I referred patients to the social worker assigned to gynecologic oncology clinic. I shared the social worker’s business cards when needed and followed up with her when appropriate.

Regardless of the particular patient and our relational connection during interviewing, there remained an undertone of clinical communication. Given the population of interest, their health status, and the context of what was discussed, I am in favor of having a clinical communication undercurrent because it helped foster a tone of safety. Some of what was discussed was uncomfortable. Having hair loss and quality-of-

life as the central focus was at times uncomfortable to some, but the tone was inclusive and the discursive space of the interview was safe partially because of the clinical context. As cancer patients, they are familiar with disclosing the personal. Our interviews addressed how the social influences the personal and vice-versa. Knowing I was trained by Moffitt (and USF) and overseen by Dr. Shahzad and the clinical staff added legitimacy to the interview process. This probably damaged the opportunity to cultivate support paralleling that of a friend or family member (Ellis & Patti, 2014), but having such an opportunity was not part of this project's aim.

### **Applying Method**

The method used to perform a thematic analysis is explained in the following section. I discuss the interview timeframe and how interviews were recorded and transcribed. Data were analyzed using a coding method, and I describe how codes and themes were developed.

Interviewing took place from October 2016 to April 2017. Supplemental data consisted of over 200 hours of organizational observation. Every interview was audio recorded except for one. In the one case it was not, detailed notes were taken and notes were typed immediately after the interview ended. There were times I had conversations following the consent process that were not recorded because of their brevity, or the setting was too public, or they were too personal and turning on a recorder was not appropriate. These conversations were not categorized as interviews and do not contribute to the total number of interviews. Each of these instances was noted in an Excel file where notes about each interview were categorized.



Audio files of interviews were transcribed by a HIPPA compliant transcription service specializing in medical transcription. After the audio files were transcribed, I performed audio checks to ensure transcription was accurate. During the checks, I took detailed notes and listened to audio files and read transcripts multiple times between December 2016-April 2017.

**Open, axial, and selective coding.** My coding procedure was influenced by Strauss and Corbin's (1990) and Charmaz' (2000; 2006) work in comparative analytics, where codes and themes are generated and revised throughout the analysis to show relationships in the data. Codes were developed based on Strauss and Corbin's (1990) three-stage approach. The first stage is open coding and involves the researcher examining, comparing, and categorizing data (p. 61). I listened to audio files and read through transcript data several times to create tentative labels for chunks of data based on interpretations emerging from actual interviews. Properties of the code (i.e., descriptors) are listed as evidence of the open code and participants' narratives are placed next to properties (open code, properties, narratives).

The second stage, axial coding suggests researchers examine context and consequences of interaction to develop a procedure "whereby data are put back together in new ways after open coding by making connections between categories" (p. 96). The properties that helped generate open codes are no longer needed, and open codes are listed next to axial codes to show consistency and progression. Lastly, selective coding is performed to determine core categories, "systematically relating [core codes] to other categories, validating those relationships, and filling in categories that need further refinement and development" (p. 116).

The three stages of coding data were completed based on mutual consensus among research team members using a representative sample of interviews transcripts. Once a consensus was reached, a coding schema was developed using open, axial, and selective codes then collapsed into selective codes representing broad categories representing patients' experiences of chemotherapy-induced alopecia. The schema was designed to recognize data relevant to the research questions guiding the study (Roscoe et al., 2016). Potential or existing discrepancies during interpretation and categorization were discussed and resolved in meetings with members of my dissertation committee. The table shown on the next page is an excerpt from the coding document and exemplifies the coding process that resulted in the selective code and category "gendered visibility" to address research question one.

TABLE 1: CODING EXAMPLE

**RQ1:** How do ovarian and uterine cancer patients communicate about their experience of alopecia over the course of chemotherapy?

Open Codes	Properties of Open Codes	Axial Codes	Selective Codes	Data
<p>Changing Appearance</p> <p>Public Visibility</p>	<p>Recognizing self as someone different</p> <p>Attributes gender as a key factor in being recognized when sick</p>	<p>Visibility in Public</p> <p>Visibility at home</p> <p>Gender</p>	<p><b>Gendered Visibility</b></p>	<p>“I don’t want people to know I’m a cancer patient. Being in public is a huge issue I want my privacy, and hair loss is such a public symbol. I’m different than all the other women who have hair. I’m singled out.” (Patient 15_1, p. 3)</p> <p>“I changed the way I dressed. I intentionally wore big jewelry to look like somebody who wore scarves” (Patient 23_2, p. 3)</p> <p>“I can see they’re thinking, oh poor girl, that doesn’t have any hair or they’re afraid...I just smile and I let them know it’s okay” (Patient 3_2, p. 4)</p>

The practice of constant comparison encourages researchers to become deeply familiar with their data and maintain a sense of openness toward adjusting codes and themes when needed. Theoretical concepts emerge from the process of constantly comparing the data to existing codes and thematic categories to “create a conceptual story line or theory” (Roscoe et al., 2016, p. 1158) to best address the research questions. This is a practical approach to coding because it takes emergence into consideration. Some codes are less

useful than initially perceived while others require the researcher to revisit specificities within the data set and revise codes appropriately.

## **Conclusion**

Research questions and methods rooted in an epistemology of interpretation stand in contrast to the majority of research generated in major medical institutions. Researching potential connections between quality-of-life and chemotherapy-induced alopecia using compassionate and longitudinal interviewing may enrich the field's understanding of the problem and hopefully improve patient-centered care. As an interlude to welcome readers into the data analysis, I share two published poems inspired by my time spent with patients during data collection. I also include an e-mail sent by a patient who wanted to share her interview experience with Drs. Roscoe and Shahzad.

## **Interlude: Poetry from Process**

The following e-mail sent by a patient (name redacted) reflecting on her interview experience. The e-mail is included because it exemplifies the meaningful interaction that took place during interviews and the co-constructed nature of the interview format. The two poems were written during data collection and analysis. The interview process was emotional for patients and me. Patients like the one who sent the e-mail inspired these poems, and I have shared them with some participants who communicated interest.

6/4/2017

University of South Florida Mail - Meredith Clements - Hair Loss Study



Meredith Clements <mclements@mail.usf.edu>

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### Meredith Clements - Hair Loss Study

4 messages

Wed, Aug 24, 2016 at 12:35 PM

To: "Iroscoe@usf.edu" <Iroscoe@usf.edu>, "mian.shahzad@moffitt.org" <mian.shahzad@moffitt.org>  
Cc: "mclements@mail.usf.edu" <mclements@mail.usf.edu>

Hello Dr. Roscoe and Dr. Shahzad,

I wanted to reach out to you both regarding my encounters with Meredith Clements and the Hair Loss Study. We have communicated by phone, email, an initial meeting and now an interview. I was excited and honored for the opportunity to participate in the study but a bit guarded because I didn't know what to expect.

I must say that it has been a very pleasant experience. Meredith, with her knowledge, approach and compassion has made the process a great experience and she is obviously a great asset to this project. Her questions are very thought provoking and she helped me to shed some light into some deeper emotions but the questions were not invasive nor did they make me feel uncomfortable. Meredith is very professional but with her obvious compassion, she made me feel comfortable in opening up and digging deeper behind why I was having some of the feelings or reactions to my hair loss.

I just wanted to pass along this information on my experience with Meredith. She's definitely working in her niche and I'm sure the feedback that she is gathering will be invaluable to the study and have no doubt that the information will be well representative of what we, the patients, have provided.

Thank you for your time and allowing me to share my interview experience with Meredith.

**Figure 1.** Patient e-mail describing her interview experience.

## 17 Lines About Chemo

Meredith L. Clements, MA

All along there's been a tumor  
Distant friends and strangers can't see my diagnosis.

It's my secret to reveal  
Until I lose my hair.

How do I respond to a child at church  
Who says I look scary without eyebrows?

I'm missing my Self  
Missing the days I complained about the baby weight  
Missing the ability to have a bad hair day.

Another women is taking my place as the attractive soccer mom  
And I'm ashamed to admit I care.

Is there space in our society to talk about chemo and aesthetics  
Or am I bound to play the role of a fighter  
Whose only concern is survival?

Am I allowed to say  
There are times I want to give up the chemo  
For one more day of looking like my normal Self?

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**Figure 2.** Poem inspired by patient population.

## AD LIBITUM

### Having Cancer and Seeking the Point

Each morning, I sip coffee on the porch Watching  
the backyard come alive  
Deer walk their usual path through my garden  
One locks my gaze, and  
I remember to breathe

She recognizes me  
I sit straight, trying to present my best Self  
Yet she remains underwhelmed by my presence In this  
moment I become more mindful  
There is humor in thinking nature might stop for me

Perhaps the point of cancer  
Is to recognize the uncomplicated nature of dying? Like  
the deer, I am not intimidated  
I have locked death's gaze  
Refusing to blink first

I am as furious as I am thankful  
For this new state of normal  
Cancer brings me to a point of understanding  
How dying is easier  
Than our medicalized society suggests  
This is my truth I keep from those  
Who are yet to be burdened by disease

*Meredith L. Clements, MA*  
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**Figure 3.** Poem reflecting patients' experiences with death and dying.

## CHAPTER FOUR: FINDINGS AND ANALYSIS

### **Introduction**

Florida is a heavily populated, steadily aging state hosting residents with serious medical problems, which makes it a strong site for conducting research that advances patient-centered care related to side effect management and quality-of-life during chemotherapy. This dissertation project took place in a major cancer research institute in Florida and helps address the need for more interpretative analyses performed by health communication scholars examining how cancer patients communicate experiences in the clinical context of major cancer centers (see Ellingson, 2003; 2005; Roscoe et al., 2013). Efforts to improve patient-centered care can benefit from learning how patients actually experience the potentially knotted entanglements (Sheep et al., 2017) of quality-of-life and chemotherapy-induced alopecia. Because patient-centered research *is* meaning-centered research, an emphasis on communication is critical.

In this chapter, the findings from the data analysis are argued from the perspective of health communication studies. The data provided rich insight into ovarian and uterine cancer patients' experiences of chemotherapy-induced alopecia (CIA) and its connection to quality-of-life (QoL). A thematic analysis of interview transcript data resulted in four major themes that will be presented in this chapter. Excerpts from the data set of 55 interview transcripts are presented as evidence in support of four themes:



1) chemotherapy-induced alopecia and quality-of-life; 2) the “mirror moment”; 3) performance of social roles; and 4) gendered visibility. Some excerpts from interview transcripts have been altered for phrasing purposes. For example, an excerpt from the transcript of Patient 23’s second interview is used to exemplify how her role as a career woman influenced how she managed alopecia. The eight sentences she speaks in explanation are shortened to three by excluding repetitive sentences and using ellipses. The communicative context is not altered, nor is the intent of patients’ perspectives.

These four themes establish that chemotherapy-induced alopecia is a quality-of-life issue for patients who experience distress related to hair loss. How patients communicate about their experience of alopecia and strategies to cope with it over time exists in tension with how they communicate about quality-of-life. Sheep, Fairhurst, and Khazanchi’s (2017) work on dialectical knotting based on Baxter and Montgomery (1996) and Baxter (2011) is used to explain the tensions between quality-of-life and chemotherapy-induced alopecia.

Sheep et al. (2017) explain, “Knotted tensions can be amplifying (exacerbating) or attenuating (improving) in their effects on one another” as they tighten and loosen over time (p. 463). Each knot has a different consequence to patient care and quality-of-life during hair loss, coexisting as a web or network of experiences that forms an “inseparable entanglement of interdependence” (Sheep et al., 2017). Similarities and disjunctions across patient interviews form a network of knots consisting of tensions among experiences.

While the two research questions that guided this research were useful in organizing the literature review and developing interview questions, the findings reveal a

single research question is a more useful framework for examining CIA and QoL over time. The revised research question is: How do ovarian and uterine cancer patients communicate about their experience of alopecia and its impact on quality-of-life over the course of chemotherapy?

Ovarian and uterine cancer patients may feel more supported and able to discuss CIA if healthcare practitioners put it in conversation with quality-of-life. The inverse is also applicable. Efforts to evaluate patients' quality-of-life should incorporate hair loss into clinical conversations because it is a topic that often leads patients to disclose other issues of concern. Doing this can better gauge the degree to which a patient's concern for the public's perception and perception of self will impact her quality-of-life during and shortly after cancer treatment. This is discussed further in this chapter and in the concluding chapter. A frame through which the data are conceptualized is argued in the following section of this chapter. A description of participant demographics follows, and the coding process used to analyze data is reviewed. Four primary themes are presented along with sub-themes and excerpts from the transcripts to exemplify each theme.

## Participant Demographics

A demographic table is listed below detailing data concerning who was interviewed and what demographic information was collected.

TABLE 2: PARTICIPANT DEMOGRAPHICS	
Demographic Variable	%
Ovarian Cancer	74
Uterine Cancer	26
Recurrence	35
Married/Partnered	61
Single/Divorced/Widowed	39
With Children	74
Without Children	13
Unspecified	13
Heterosexual/Straight	91
Homosexual/Lesbian	4
Unspecified	4
Caucasian	79
Hispanic	17
African American	4
With Health Insurance	52
Unspecified	35
Hospital Charity Care Program	9
College/Some College/Technical	39
Unspecified	30
Postgraduate	17
High School/Some High School	13
Total Participants (n= 23)	
*Avg. Age= 62 years (39-83 years)	

Longitudinal qualitative interviews resulted in a data set composed of 55 interview transcripts, yielding approximately 1,750 minutes of audio (29 hours) from a population of 23 ovarian and uterine cancer patients. Interviews averaged 76 minutes total per patient and were performed over 14 months beginning in February of 2016. Interview duration ranged from 34 minutes to 132 minutes. Each of the 23 participants

was interviewed at least twice either in-person or via telephone after informed consent was gained in-person. Seventy percent of participants were interviewed twice and 30% were interviewed 3 or 4 times. More specifically, 16 patients were interviewed twice, 5 were interviewed three times, and 2 were interviewed four times. The average interval between interviews was 19 weeks (4.8 months). The shortest interval was 1 week and occurred between interview 2 and interview 3 with Patient 1, while the longest interval was 44 weeks between interview 1 and interview 2 with Patient 9 and Patient 11, resulting in a range of 1 week to 44 weeks. The two range points (1 week and 44 weeks) are outliers, as the most common intervals between interviews was approximately 4 weeks to 12 weeks (among 43% participants).

Each patient considered the cancer center where this research was conducted as her primary provider of cancer care. Almost all participants identified as straight/heterosexual. Of the two patients who were insured through Moffitt's "charity plan" one said her high quality-of-life (4.5 out of 5) was strongly associated with this coverage. She explained, "Before I was accepted, my quality-of-life was a 1. I knew what it was. I knew the cancer was growing and there was nothing I could do. I was filling out the paperwork for Hospice when I found out I was accepted to receive charity care.

Among the demographic data collected, age, marital status, and parental status were the three that had noteworthy influences on patients' perceptions of managing alopecia and its connection to quality-of-life (QoL). Women with children and grandchildren almost always mentioned how their alopecia affected their role as a mother or grandmother, and most were hyperaware of covering their heads when interacting with

children. There was a division in perspective among participants as to whether age was a factor in experiencing alopecia. Some described their age as one of the primary reasons they could manage being bald while others said they would have similar feelings at a younger or older age toward being bald and being recognized in public. Patient 13 explains the importance of age saying, “Yes, age is a factor. I’m in my fifties. If I were younger, it would have been far worse. If I were in my thirties or forties, it would have a stronger impact. For me, it matters because of the privacy...but it’s not a top concern” (Patient 13\_3, p. 13).

Age was often an impetus for rich discussions about their romantic lives and marital status. While marital status is not synonymous with a specific degree of romantic activity or a certain level of appearance management, it was for many participants who were married or partnered. Findings argue age and romantic status are entangled. All who were widowed said they would be more concerned with their hair loss if their husbands were still alive. Patient 22 explained, “Age is not a factor. It depends on the circumstances and needing to appear attractive to others...of being in search for something or someone. I’m not in search of someone. I became a widow 26 years ago. I would handle hair loss differently if he was alive” (Patient 22\_2, p. 8).

For some, romantic/marital status and age were not understood as an “either/or” but rather a “both/and” issue with one taking precedent. For example, when asked how age and marital status impacted her experience, Patient 16 suggested both were central. “...When you are young, it would bother you more...If I live long enough for my hair to come back, who knows” (Patient 16\_1, p. 2). It is worth noting Patient 16 lived long enough for her hair to grow back and decided to purchase a wig but did not want others to

know she is wearing one. More details on how age, marital status, and parental status impact the experience of alopecia are provided within the descriptions of the four themes generated from the data.

The 29 hours of audio recording transcribed for analysis make up approximately 15% of the total time I spent in the clinic. From February 2016 to November 2016, I spent approximately 210 hours in the clinic. For 5 months after November 2016, I continued to visit the clinic but only for brief periods of time to conduct follow-up interviews or to use the computer system and maintain relationships with staff. I did not count that time toward the 210 observational hours because I did not take observational notes except for notes directly pertaining to the time spent conducting interviews.

Over the fourteen months spent in the clinic, I became familiar with the organizational culture and was able to focus my research efforts on interacting with patients and less time learning the workflow of the clinic, particularly how patients are moved through their appointments. Interviews relied on participant availability, but a patient's schedule is largely out of the patient's control. An appointment in the gynecologic oncology clinic often takes place between multiple appointments in other clinics within the cancer center. Also, a participant might be visiting the gynecologic oncology clinic for a routine visit while others involved critical decision-making to determine changes in a patient's treatment plan. Because of this, phone interviews became more common, especially during the middle phases of participants' chemotherapy, and I continued to check-in with them in-person.

The consent process spanned February 2016 to August 2016. The first round of interviews was completed by the end of August 2016, and I remained in formal contact

with some patients until April 2017 though some of our interactions include informal check-ins to maintain relationships and thank patients for participating. I still maintain informal contact with a few patients but do not include our communication as data for this analysis.

Twenty-eight participants consented to participate. Upon further review of inclusion criteria 2 did not qualify. Three of the 28 were unable to work interviews into their treatment schedule. None of the 5 who were excluded from the data set voiced concern for participating or directly stated they wanted to withdraw from the study, but it was clear their participation needed to be discontinued because of the demands of treatment. Therefore, 82% of those who consented completed two or more interviews and were included in this dissertation's data set.

One of the original goals of data collection was to interview each participants 2 to 3 times, but the reality of these patients' illnesses and the demands of treatment prevented consistency. The range in numbers of interviews per participant shows the reality of in-depth interviewing with seriously ill patients undergoing chemotherapy. Data collection of this type is messy. There were many times conversations occurred but were not recorded because it did not fit my ethic of interviewing and would have been insensitive to interrupt and ask for permission to record. Aligning with Ellis and Patti's (2014) argument for compassionate interviewing, participants' well being was positioned ahead of a self-determined goal to amass a certain number of interviews according to a fixed schedule. After all, this project analyzes quality-of-life, thus it makes sense to practice methodological sensitivity and embrace the inconsistencies of the data set and interpret the complex messiness that is the patient experience.

## **Thematic Analysis**

A thematic analysis of the data revealed four primary themes: 1) chemotherapy-induced alopecia and quality-of-life; 2) the “mirror moment”; 3) performance of social roles; and 4) gendered visibility. Excerpts from the data set of 55 interview transcripts are used as evidence in support of each theme.

### **Theme 1: Chemotherapy-Induced Alopecia and Quality-of-Life**

Analysis of the data reveals chemotherapy-induced alopecia (CIA) as a quality-of-life (QoL) issue that changes in its importance over time. The relationship between CIA and QoL exists in tension, what Sheep et al., (2017) refer to as a knotted tension, where the strength of connectivity tightens and loosens depending on other variables such as how effective the chemotherapy is or how supported the patient feels, among other interrelated issues. The theme, “chemotherapy-induced alopecia and quality-of-life” was developed based on multiple axial codes including: public interaction, functioning/active, isolation, dying, managing appearance, control/loss of control, relationships, loss, abnormal/normal.

Theme 1 of the analysis explains how CIA impacted patients’ QoL over time. The language used to describe CIA as “temporary” was complicated by patients’ perceptions of their health status. Unfortunately, if a person has been diagnosed with an end-stage disease, life itself is temporary along with other symptoms, issues, and relationships. An interview question asking patients to rank their QoL from 1-5 over the course of chemotherapy yielded data suggesting the ineffectiveness of scale-based QoL questions unless they are paired with follow-up questions asking “why?” In addition, the “falling out” and “mirror moment” stories and the head shave were identified as specific



moments along an uncertain trajectory of chemotherapy with patients interpreting the shave as a way of enacting control over a largely powerless situation. The “mirror moment” will be discussed in greater detail in the second theme.

One of the more useful findings to emerge from the data was the need to expand what is and is not included in discussions of quality-of-life. Patients who were not in remission explained how their failing health status continued to mutate their imagined list of “quality,” shifting certain priorities and reinforcing others. Patient 13 explained:

**“It’s not like I’m going to recover and get my hair back and live the rest of my life,** which is the case for a lot of breast cancer patients. They’re going to lose their hair and eventually going to get it back and go on with their life...**For me it’s more of, ‘okay it’s a different life now.’ Nothing is the same. None of the rules are the same...**I can see where women would feel [the way I do] because **I’ve always had longer hair”** (Patient 13\_2, p. 6).

Patient 13 lost her hair twice and almost always wore a wig in public. Though exercising and eating healthily remained important elements in maintaining her quality-of-life, Patient 13 clarified how the meaning of “being healthy” has shifted over the years of living with ovarian cancer. The idea of transitioning out of treatment and out of baldness does not apply to her lived reality. Patients who shared this viewpoint said “getting back to my normal self” and “looking like my normal self” were impossibilities because of the severity of the cancer and the corresponding treatment plan. Patient 19 said QoL with recurrence involves mindfulness in recognizing “your new normal.” Patient 9 reported a similar shift in “quality,” saying she always associated QoL with family and having interests (i.e., hobbies) but CIA made her feel like she had to “look

more normal” for family and hobby-related friends in order to continue having meaningful interactions. “[I want to] look as close to normal as possible to make other people who are bothered by you not having hair, to make them feel better” (Patient 9\_1, p. 52). Social/familial relationships and her appearance were not as strongly associated before CIA as they were after she lost her hair.

Many of the first-round interviews with patients who were enduring chemotherapy for the first time included descriptions of CIA as “temporary.” In contrast, patients experiencing recurrence rarely used words like “temporary” to describe their baldness because most thought of their alopecia as part of their dying process. Patient 9 said her hair was not returning fast enough to keep up with the pace of her dying, saying it needed to grow faster so she would not have to wear hats and caps for the remainder of her anticipated six months of living. Another patient in recurrence said, “If I live long enough for my hair to come back, who knows” (Patient 16\_1, p. 2). These participants and others who shared similar stories did not see alopecia as a fleeting side effect because it was more of a lasting aspect of their lives as they moved in and out of treatment or they neared the end of life.

Other patients reiterated Patient 13’s point about “nothing being the same” in reference to their overall lived experience, including issues of aesthetics. Having “always had long hair,” Patient 13 did not perceive ultra short hair as a significant improvement. For Patient 13, managing appearance used to be motivated by personal preferences, but chemotherapy changed this. Years of alopecia along with slow phases of regrowth then beginning chemotherapy again shifted her perception, saying she wore wigs “mainly for others.” For Patient 13, appearing professional and “maintaining professionalism” were

contributing factors to quality-of-life. Wearing wigs became a way to maintain professionalism because “they are less of a distraction.” Because of this, hair loss and wearing wigs became part of her quality-of-life in terms of her professional interaction.

Some participants made strong connections between their actual hair and their quality-of-life. Patient 5 described losing her hair as **“I miss my hair...it was the hardest thing.** It’s what I do [as a career]. It’s what I did. I didn’t expect for this to happen...”(Patient 5\_1, p. 4). This was a shift from the first interview before losing her hair when she said it “is just part of the process,” framing it as temporary and unimportant. **“I’m not going to wear wigs** I don’t think. [Hair loss] is inevitable and I have cancer and hair loss is part of it...**I’d feel fake**...my mom thinks I should...”(Patient 5\_1, p. 4). Her perspective continued to shift, saying, **“When I first got the wig, and found out I couldn’t sleep in it I thought, oh damn it...[but] it’s not as important as I thought ”** (Patient 5\_2, p. 11). Over time, CIA oscillated in importance, from a non-issue, to a major concern impacting social interaction, to becoming less of a concern.

Another example of how perceptions of CIA change over time is exemplified in an excerpt from Patient 16’s interview.

**“There is an immense connection between hair loss and quality-of-life...The Bible says hair is your crowning glory...When I first shaved my head I thought, gee, I look like my father, and I put my scarf on immediately...Hair loss did not become more of a concern until after the third round [of chemotherapy]”** (Patient 16\_2, p. 14).

Wearing a scarf immediately after her head shave suggests an attempt to assuage the shock of sudden change, what Yoshino's (2006) work on covering calls "a toning down of disfavored identity to fit into the mainstream" (p. ix). The initial shock withstanding, Patient 16's experience of alopecia worsened over time. She continued:

**"I guess it would be like someone who has breast cancer losing their breasts.**

**I feel like they've lost their femininity...Losing my hair was horrible.** I was prepared [to lose it], but they have this darn television commercial that says if you are on –and they listed my drug! The next time I saw Dr. [name] I said, just tell me if it won't grow back...**your dignity is your hair"** (Patient 16\_2, p. 5).

Following Sheep et al.'s (2017) argument for relationships existing in a state of tension, data show patients who identified with a feminine perspective established strong connections between QoL and CIA. The social standards of femininity do not resonate with all patients who reported alopecia as a top concern during chemotherapy. For example, Patient 7 said she and her husband were bohemian and neither had cut their hair for years. "I have long hair like an old hippie, keep it in a ponytail. No maintenance. After [hair loss] I wanted to approximate that look as quickly as I could" (Patient 7\_1, p. 3). To prepare for hair loss, she cut off her ponytail "wrapped it in tissue paper and stuffed it in a Ziploc bag" (Patient 7\_1, p. 2).

For most participants, CIA became an issue of greater concern over time following the trajectory of chemotherapy. This makes sense considering how the initial concern, for most, is enduring chemotherapy for the sake of surviving. As the concern for survival dissipates, concerns for aesthetics often increase.

“Survival and treatment were [my main concerns]...now it’s not as much of a priority **since my health is coming back**. You start concentrating on other things like appearance and your hair. **Hair loss was number four of my top concerns but moved up the ladder after I settled down from the initial shock and started chemo**” (Patient 15\_3, p. 8).

Patient 15’s perspective illustrates the experience of many. Patient 1 was more detailed in describing how her concern for CIA changed over time. During the third interview, she shared the following:

“What’s changed? My hair, that’s it. Yeah you want to cover it up. Before it didn’t bother me that much. But when I go out now, I cover myself. **Before I couldn’t care less, so now I’m starting to feel better so I want to ya know try and look better**...but I’m not feeling like I look good. I put lipstick on. I mean I lost a lot of weight. I can see that. I haven’t got to a point where I feel comfortable. I haven’t gotten to a state where I feel, gee I look good” (Patient 1\_3, p. 2).

When asked to define quality-of-life, Patient 1 wrote, “going out to eat with family, being my own person, not to be waited on by anyone, walking by myself, being me.” Social interaction was a key component in Patient 1’s quality-of-life, and CIA prevented her from enjoying outings like going to restaurants and the beauty parlor. She elaborated further on the issue of CIA and QoL when chemotherapy had ended but her hair had yet to return.

“It’s annoying. You know, it bothers me because **I look to see if it’s growing back [because] I can’t wear the wig all the time**” (Patient 1\_4, p. 3). She

continued, **“I miss the hair...a lot of times I think about going to the beauty parlor [but] I cant go [because] I got no hair”** (Patient 1\_4, p. 10).

Patient 1 was less prepared for the slow return than the falling out, struggling to understand how she was still unable to engage in social activity in the ways she wanted though she had completed chemotherapy. Patients were well aware their hair would fall out during the first phase of chemotherapy and reported being told this during the consent process before chemotherapy. Most remembered the nurse who did the consenting telling them and/or their physician. According to participants, the “telling” happens only during pre-chemo conversations.

Data provide evidence of the CIA experience growing increasingly more difficult over time, yet the initial pre-alopecia/ pre-chemo conversation is the one conversation participants referenced. Few patients reported feeling unprepared for hair loss. When asked why, almost all said, “because Dr. [name] said it would happen.” For example, “They didn’t offer any suggestions, but he told me when it would fall out. You know, how many days after the first chemo” (Patient 23\_1, p. 1). Preparation seems to be adequately addressed in the clinic, yet the “during” phase of CIA seems to garner little attention from the patients’ perspectives. This is a missed opportunity for ongoing communication that could lead to a higher quality of care. An excerpt from Patient 15’s third interview transcript exemplifies distressing thoughts some patients experience during CIA but do not share in the clinic.

“There is a question, Meredith, that you should be asking. I don’t know my answer to it yet, but **you should ask, ‘if you have to go through chemo again and you know you’re going to lose you hair, would you do it?’** Because I’m

thinking, if I have to do this again and have the taxol and lose my hair [pauses, takes a deep breath] would I do this...**I guess I would but geeze that's probably the first thing [laughs] I'd think of is, I'm going to lose my hair again. Not I'm going to get neuropathy or I'm going to be constipated, it'd be I'm going to lose my hair again.** That would be, ugh, that's hard...it would distress me thinking of doing that again" (Patient 15\_3, p. 11).

Another participant inadvertently responded to Patient 15's question when describing how she feels about CIA after completing chemotherapy.

'I could much more easily go without makeup than my hair...**If somebody said to me we'll heal you and let you keep your hair obviously I'd [prefer that]...I'm sure there would come a point in your disease where you wouldn't be physically able to have a wig on and that's very sad. God willing I won't get to that point before [recurrence] and my hair will be coming back"** (Patient 6\_2, pp. 9-10).

Patient 6's statement along with her description of CIA as a trauma she had to overcome position CIA as a quality-of-life issue. As Patients 15 and 6 reflect on the possibility of recurrence, hair loss and being bald are immediate concerns.

Unlike Patients 15 and 6, Patient 11 is experiencing recurrence. The first time Patient 11 lost her hair, she was shocked and rarely left the house. A self-declared realist, Patient 11's perspective shifted, now compartmentalizing CIA using a business-like approach from her years in business.

**"This is my second time around [with cancer] so I knew I was going to lose my hair. No doubt, I had zero hope for keeping my hair this time...I've changed**

**over time**” (Patient 11\_1, p. 3). She later stated, “It is kind of **like a business thing to me**. It’s like okay, it is part of my life I set aside when it is necessary to think about” (Patient 11\_2, p. 1).

Patient 11 was told she outright both times she would lose her hair, yet she kept hoping she would be the exception. Such hope speaks to the larger experience of being a seriously ill patient, holding onto hope against odds, highlighting only the “probably” in the statement, “you will probably lose your hair.” Now retired, she “ran” her cancer and chemotherapy as a business, attempting to separate issues of cancer from other areas in her life like church and music that brought her enjoyment.

Patients had difficulty providing overall reflections of a six-month to multiple year account of one’s experience with CIA and were not expected to do so. As natural storytellers, participants most commonly shared their hair loss experience by telling two specific stories: a “falling out” story detailing the time they realized their alopecia was actually happening and the head shave story about their decision to shave or not and why it mattered.

**The falling out story.** Every patient shared a “falling out story,” accounting specific moments when their hair loss became a reality. Some descriptions span the length of a page or two, including when hair loss began and the rate at which it happened. They shared where they were, what they were doing, who was with them, how they reacted, and what they did with the excess hair. Patient 7, for example, added her clumps of loose hair to a bird’s nest in her backyard, thinking it could be put to use instead of discarded.



The falling out story was usually told in conjunction with descriptions of their head shaves, which were perceived as a way to take control of a largely powerless health situation. The falling out story was told differently from the head shave story, which was more closely linked with control. Both the falling out story and the head shave were critical moments in the alopecia process because they marked specific times when their status as a cancer patient became visible. For some, the initial phase of CIA was the most distressing because it “made it all real” but for most the head shave was the most dramatic and traumatic.

The falling out story was most commonly told using three, overlapping subjects. First is a story of surprise and curiosity (e.g., “I woke up with tiny hairs all over my pillow and thought, what is happening to me”) while another is a more organic, process-based story of acceptance (e.g., “I kept brushing my hair until it all eventually came out”). Lastly, some patients’ spoke of taking action, telling their falling out story to segue into their head shave story (e.g., “then I went and did something about it”). Patient 6 exemplifies the idea of surprise in saying, **“We don’t really think about it [falling out] until big clumps of hair start coming out and then it’s like oh my gosh is this really happening** and then you have to deal with it...” (Patient 6\_2, p. 9).

Patient 6’s idea of alopecia did not include clumps of hair and calls attention to the difference between being bald and being bald because of chemotherapy. Likewise, Patient 5 told her story using a process-based description with a bit of unexpectedness.

“I didn’t lose my hair when I was supposed to so **I thought I would keep it. Then surprise, it started coming out in splotches.** I kept the long strands and gradually cut it. **It’s coming out again in wisps**” (Patient 5\_2, p. 8).

Though Patient 5 was told pre-chemotherapy she would lose her hair, the loss was surprising. Patient 5's treatment plan involved the sandwich method, where patients undergo surgery in the middle of the six cycles of chemotherapy. Because of this, she had a small amount of hair return then lost it again after restarting chemotherapy. Most patients who spoke of hair loss happening twice (or more) did so in reference to recurrence, but Patient 5 was halfway through her first chemotherapy. Yet it made sense Patient 5 would speak about CIA as happening "again" given how highly she valued her hair. Patient 3 communicated less attachment to her hair, telling her falling out story as a series of action steps.

**"I had patches [of missing hair], so I said well I don't look any good with this so we called a friend of ours who is a hairstylist and she came to our home and shaved it. I feel much better without the hair because of the patches. I didn't look good"** (Patient 3\_1, p. 2).

Other participants reiterated Patient 3's comment about "feeling better" after taking action. Some said they experienced physical discomfort during "the falling out." Some described their hair as feeling heavy and their scalp tender. Patient 10, for example, developed sores on her scalp and face, which she listed during the second interview as one of her top concerns.

Patient 12's falling out story is memorable for taking action almost immediately. Her falling out story shows the curiosity behind the phenomenon of experiencing alopecia, as she continued gently pulling out her hair until she felt it was time to shave it. She describes:

**“After the first treatment, I started losing my hair...[a few days later] I was sitting on the front porch and a bug flew in my hair, and by the time I ran my fingers through my hair [to get the bug out] I had a handful. I turned around and just kept doing it, running my hand through my hair and by the time I finished, I had a pile of hair in front of me on the ground probably four inches tall. I just sprinkled it in that one area. My daughter saw, and I said, ‘well you might as well shave it.’ I can’t even cook food for anybody because I’ll get hair in the food...”**(Patient 12\_1, pp. 9-10).

Cooking and enjoying meals are an aspect of Patient 12’s quality-of-life. When asked to describe what quality-of-life meant to her, Patient 12 mentioned spending what time she had left with her family. When asked what her top concerns were during chemotherapy, not being able to cook while her hair was falling out was among the top three. These responses demonstrated how QoL is often conceptualized as a “deathbed” moment reserved only for a few top tier issues. In Patient 12’s case, these top tier issues were family and time and lower tier issues were appetite, hair loss, and cooking.

Including the lower tier issues can enhance the conversation and enable a better understanding of Patient 12’s perceived difficulties in managing the side effects of chemotherapy. During both interviews, she repeatedly mentioned how unsettling it was to cook for the family only for them to find her hair in the food. These stories made her laugh and cry. Hair in her family’s food was an emotional element of chemotherapy. Patient 12 was one among other participants to make this connection, which is understandable when considering the important role of food in social gatherings and familial relationships.

**Quality control: The head shave.** Head shaves were communicated as specific moments during chemotherapy-induced alopecia when patients took control over a largely powerless health situation. All of the 74% who shaved their heads communicated control regarding where it happened, how, when, and sometimes who was included. The head shave was significant because it marked a specific moment during chemotherapy when participants became recognizable as cancer patients, yet they had some control over when this happened. Deciding where, when, and how something health-related happens was rare during chemotherapy. The head shave is the tipping point for a changing appearance that leads to a mirror moment and heightened gendered visibility. Both of these themes are discussed in detail later in this chapter. The mirror moment theme addresses the personal elements of seeing oneself as a cancer patient, while the gendered visibility theme speaks to the social experience of being recognized as a woman with cancer.

Those who shaved their heads were sure of their decision, saying they would advise other patients to plan a head shave.

**“Some people expect [hair] to completely fall out on a certain date...they should consider shaving it to just get it over with quick”** (Patient 23\_1, p. 6).

**“Once my hair started falling out I just wanted to get it shaved off...I don’t want to see it piece by piece, I can’t. I know it’s going to happen. Just do it”**

(Patient 22\_1, p. 1).

Patients 23 and 22 communicated a “get it over with” and “just do it” approach, identifying head shaving as the easier method of managing alopecia. Patients 2 and 8

shared stories that support Patients 22 and 23, framing the head shave as a relief instead of a troubling experience.

**“My hair was getting in my face, my eyes, my mouth and I felt it falling down my back...I said it’s one of two things. You take me to the salon and let them shave it or you can cut it...It was a relief really”** (Patient 2\_3, p. 5).

**“Saturday night when I woke up I felt prickly all over because there were hairs sticking in my face. I live with [adult daughter] during this time, and I asked her to please shave it off because I don’t want patches and I don’t want to deal with the tickling. And she did”** (Patient 8\_1, p. 5).

Patients often chose to have a loved one shave their heads in their homes for privacy or practicality, which was highlighted in Redgrave et al.’s (2004) autobiographical research and inspired how the data was coded for the head shave story and mirror moment theme.

Patient 21’s head shave story best illustrates the connection between control and the head shave and the important role the head shave plays in the post-shave experience of confronting a mirror’s reflection, leading to the “mirror moment” theme.

**“I cut off the majority of it myself and then my son just buzzed it off. I think it would be more traumatic to have it start falling out on its own...I felt like I was starting [chemotherapy] in control. My diagnosis I couldn’t control, but the losing the hair part even though it all left, I could control that”** (Patient 21\_1, p. 4).

Controlling the planning of her head shave led to an understanding of head coverings as issues of control as well. She later said, **“It’s all about control...If I don’t wear a hat I**

**feel exposed**, like I'm going to be approached...**so control and not exposing myself...**"(Patient 21\_1, p. 20). In analyzing the transcript data, it seems the way she approached the head shave framed the outlook for how she approached head coverings, demonstrating the connection between a specific moment (the shave) along the trajectory of managing alopecia (wearing head coverings).

Patient 21 shared a photo of the moment described above. As mentioned in the literature review, Redgrave et al.'s (2004) work features a similar photograph. The image shows Patient 21 seated in front of the bathroom mirror wearing a black smock. She is looking in the mirror without smile or frown, holding the cell phone camera at shoulder height to capture a straightforward angle. Standing directly behind her, her son's face is aimed downward, kissing his mother's newly shaved head. Patient 21's decision to document the head shave moment through photography was profound and further demonstrates how controlling the timing of the moment does not neutralize the emotional experience.

Some of the six who did not shave their heads did so to avoid the emotional experience represented in Patient 21's excerpt. Patient 19 explains, "I didn't shave my head. **I just allowed it to fall out as it wanted to.** Little by little it fell out then on day, I'm bald. **[Shaving] is too emotional. Too shocking. Too much**" (Patient 19\_1, p. 1). Of the total, 74% of participants shaved their heads. Others reiterated her sentiment, saying shaving would be "too drastic." Patient 19 went on to say, "**...some women they're pretty strong to have their hair shaved off.** It's such a shock. Truly" (Patient 19\_1, p. 9). Her strong opinion against shaving her head was uncommon in the data set,

yet it attests to the control patients demonstrate over deciding when and how to approach a head shave, including rejecting the idea and “allowing it to fall out as it wanted.”

The head shave can become a social moment in CIA. Multiple participants shared stories of support involving loved ones. For example, Patient 10 planned a “head shave party” with friends and family, saying she was making a dark situation lighter. The first excerpt featured her pre-shave planning and the second excerpt is from months later.

“One way I’m going to try and make it a little easier, **I’m going to have a head shaving party when the time comes.** I have a friend that’s a hairdresser...a lot of friends and family are going to go. **Some have already said they’re going to shave their heads too. My mom wants to do it but I won’t let her. I’ll host a party and maybe a pub-crawl after just to try and lighten the situation I guess.** They’re all looking forward to it” (Patient 10\_1, p. 3).

The second interview began with a discussion of if the head shave party happened and how it went. Similar to another participant, Patient 10 wanted to get ahead of the process and “shave it off before it all fell out” (Patient 14\_2, p. 9). Patient 10 describes the important of controlling the timing.

“**I was trying to schedule [the shave] with my sister’s work schedule** and one day, my hair just like fell out so bad. **I had this huge clump of hair in the shower. I said, by any chance can we do it this evening when you’ve closed?** And she said sure. I called my friends and mom and **we got a bunch of wine. We were all laughing and crying.** It was a good event to have them...**we were all crying** (Patient 10 \_2, p. 1).

When asked to define what quality-of-life meant to her, part of Patient 10's response was: "spending time with family and friends." Patient 10 was one of four participants who wrote "friends" as part of their QoL definition. This value was enacted by the way she organized the head shave, making it an event and controlling the place, time, and who was there. A couple of male friends shaved their heads in support, and she was the only participant who mentioned having friends do this (some have family members).

In a way, the head shave story encapsulated patients' cancer stories. It included primary elements of struggle and control. For Patient 10, her head shave story spoke to how she defined quality-of-life through time spent with family and friends. And it set the stage for patients sharing deeper connections among hair loss, personal reflection, and social interaction. In addition to the head shave story, participants were asked to respond to a scale-based QoL question where they ranked their QoL from 1-5 and explained their choice of number.

**Using a scale: Ranking QoL from 1-5.** Over the course of the interview process, participants were asked to rank their quality-of-life on a scale from 1-5 with 5 being the highest. There was an overall willingness to participate in the scale-based quality-of-life question though a few were unable to assign a number to their QoL because it was "too limiting." For example, Patient 2 would not respond with a number, but provided an overall assessment.

**"To me [low QoL numbers] make a lot of sense if it hurts you to do anything.**

**I mean, when your joints and your fingers hurt and your elbows and your**



**nails and your hip...everything hurts. I can't have any [quality-of-life]"**

(Patient 2\_4, p. 7)

An indirect opting out of choosing a number to QoL was the first indication of the ineffectiveness of scale-based questions to measure a problem of interest as subjective as quality-of-life. The majority of participants responded to the scale-based question at least twice over the span of multiple interviews. This question was designed with the expectation that participants would provide a number during each interview and pair the number with an explanation. In actuality, patients assigned multiple numbers to one moment in time or provided one number and explained their choice of number in a complicated manner that suggested the number was fleeting. An excerpt from Patient 14 demonstrates patients' wavering.

**"It depends on what part of [QoL] I'm looking at. Probably between a 3 or sometimes a 4. I don't know, occasionally a 2 [laughs].** It depends not only on how I feel physically but I don't like uncertainty. I have this new –I don't know if it's a tumor and I have a trip planned. **That's the quality-of-life, the tumor. But as far as how I feel probably more a 3, some good days a 4. It depends. I get tired"** (Patient 14\_2, p. 3).

In analyzing the QoL scale used during interviews, two issues of interest emerged. First, data revealed difficulty and confusion when ranking QoL on a numerical scale. Second, most participants associated low numbers with specific negative experiences (e.g., "I will not attend church without my hair") and high numbers with overall health status (e.g., "Completing chemo puts me at a 5, but I'm a 4.5 until my hair returns").

**“I guess I would say a 5 because I’m cancer free now...I did want to go on a cruise but I don’t want to go it until I have a little bit of hair. I’ll knock off a .5 because of the hair...I can’t complain”** (Patient 17\_1, p. 34).

Almost all QoL numbers wavered, with 9% of respondents providing consistent QoL numbers throughout chemotherapy. Interestingly, this 9% responded “5 out of 5” each time they were asked to provide a ranking, with one patient citing God as her reasoning. The other patient credited her daughter, grandchildren, and openness to dying as her reason for maintaining a 5 in QoL. The remaining 91% tended to link low numbers (which indicated a low QoL) with specific negative experiences and high numbers (which indicated better QoL) with larger issues and “deathbed” types of reflection (e.g., “My CA-125 numbers are low, so I can’t complain;” “I’m realizing what really matters now, and I’m doing alright”). From the data, it was apparent this patient population had difficulty associating numbers with lived experience, not because they did not understand the task, but because it did not resonate. Patient 9’s response demonstrates how some women provided a number for the purpose of responding to the question then explained its higher ranking with “deathbed” reflection.

**“I’m probably a 3 because Dr. [name] said I have 6 months to a year to live”**

Interviewer: I’m sorry to hear that. That’s heartbreaking. So with this news, why are you not at a 1? What brings you up to a 3?

**“Well [laughter] people tell you, you’ve got to fight. You’ve got to fight. So you do what you can do but you know, I don’t know what’s happening”**

(Patient 9\_2, p. 4).

Patient 9's response is evident of how the scale-based question did not yield clear or concise responses as it was expected to. For the sake of validity, it was critical to ask "why" when patients provided a numerical response. Asking "why" or "how so" may seem natural to interpretative researchers, but the current quality-of-life research using scales rarely do so (Can et al., 2013; Munstedt et al., 1997, Osoba, 1994; WHOQOL, 2002) which was useful for an interpretative study such as this because conclusions can be drawn from the messiness.

Everyday life during chemotherapy and overall "deathbed" reflections became jumbled, leading to confusion or wavering responses. Some patients experienced confusion, which is represented in the following excerpt:

Interviewer: Do you think hair loss relates to quality-of-life?

**"When my hair first starts falling out, it really bothered me because it was kind of long...so I want to say [my QoL] is a 3.5. I would love to have somebody come in and take all the furniture out of the house, redo the whole house and put in something all new and different and let me work with that. I'm tired of looking at my surroundings"** (Patient 19\_2, p. 1).

Data have determined the QoL 1-5 score is an ineffective measure if it is used on its own. It is a starting point, not a stopping point. It is a conversational opening that can uncover meaningful issues important to the patient. A numerical scale for quality-of-life is an exercise in what Hyde's (2012) work calls an opening for dialogue that raises the consciousness of patients' experiential reality as it is happening in the moment. QoL scale-based questions are effective starting points to gauge patients' willingness to look inward.

**Summary.** Considering chemotherapy-induced alopecia a quality-of-life issue first requires being open to the possibility of living a meaningful life while enduring chemotherapy. This can be difficult for some patients and their loved ones as it is difficult for society at large to place quality-of-life and having ovarian and uterine cancer in the same conversation because of the pain and terrifying uncertainty of such serious diseases. As Patient 12 said, “I got my diagnosis, looked it up online and said, ‘Okay, I’m going to die.’” The death sentence and/or survivor mentality (see Lerner, 2004) can hinder conversations about the everyday lived experience of chemotherapy.

Research encouraging patients to share stories that focus on chemotherapy-induced alopecia provided data on how most patients’ concern for hair loss increased over time, yet they reported having CIA-related conversations with healthcare providers only during the beginning of chemotherapy. Data highlighted the complications of using language like “temporary” to describe hair loss. Though many patients use the phrasing, those offering support, such as healthcare providers, should not emulate it because it often fails to resonate with patients.

Descriptions of the actual loss represented “falling out” stories that created openings for patients to share overall perspectives on coping with alopecia and chemotherapy. This provided insight into how individual patients approach their disease. Those who told their “falling out” story using a “taking action” tone tended to approach their disease in the same way, speaking to the importance of controlling what they could when they could. Most used their “falling out” story to transition into an account of their head shave. The head shave involved interpersonal elements of relationships between patients and their loved ones. Also, it marked a specific moment of control, which is

useful for conducting research on an ongoing problem that changes over time. The “falling out” and the head shave stories are used as points of analysis to research shared experience.

## **Theme 2: The “Mirror Moment:” Perception of Self and Reflection of Self**

Of the 23 participants, 65% explicitly said mirror(s) in reference to “looking into the mirror” at home a total of 28 times across the 55 transcripts. Having a mirror moment is a reflective act and an embodied experience. The theme “mirror moment” represents the private moments of hair loss when patients are alone with their reflection. Patients’ “mirror moments” materialized differently but illustrate a shared experience.

The “mirror moment” theme emerged as a selective code based on multiple axial codes, including identity, changing appearance, recognizing mortality, self-perception, and misrecognition. Data indicate participants often discuss chemotherapy-induced alopecia in a way that frames it as a social phenomenon experienced among others in the context of the public sphere. The “mirror moment” theme interprets data that are more personal than social, providing a more complete understanding of an extreme change in appearance.

**Acceptance and avoidance.** Some patients (22%) discussed avoiding mirrors, and how this effort was part of their acceptance process. Patient 10 describes:

**“We were all crying [after the head shave]. Still, we made the best of it. It was weird.”**

Interviewer: What made it weird?

**“I don’t know. I couldn’t look at myself. Like when I came home that night, I wouldn’t look at any mirrors. But I eventually got used to it. It was just a little**

bit of a shock first.... **Like that first night when I came home, actually in my bathroom, I put a towel over the mirror. I didn't think I ever wanted to look at it...**" (Patient 10\_2, pp.1-2).

Placing a towel over the bathroom mirror is a deliberate act of distancing herself from the mirror's reflection. This was unique to the home, since she obviously could not cover mirrors in public places. After the first half of chemotherapy, another woman spoke about her baldness, saying, **"I hated looking at myself..."** (Patient 17\_1, p. 22). Patient 17 always wore wigs in public and some type of covering in the house, while Patient 10 almost never wore a wig in public but did wear some form of covering. Despite their preferences, they shared a serious dislike for the mirror's reflection.

Patient 11 was experiencing recurrence of ovarian cancer. Like Patient 17 mentioned above, she always wore one in public and often inside the home, yet the wig did not help with the problem of avoiding mirrors. **"... I didn't look at myself that much in the mirror and I was at home so it wasn't... I'm not really attached to my hair that was not a big deal but I wasn't prepared for [losing] it"** (Patient 11\_1, p. 1). Patients 17 and 10 had long hair and saw it as part of their identity. Both patients were younger than Patient 11, and each had a different marital status from each other. Interestingly, Patient 11 was "not attached" to her hair, yet she held wigs in high regard, almost always wearing it while Patient 10, who covered her mirror with a towel, only wore her wig a few times throughout chemotherapy. Though preferences for head covering were different, patients shared a similar struggle with the mirror. Each discussed mirror moments to illustrate difficulty and progress.

One may assume it would take a moderate to long period of time to transition from avoiding the mirror reflection to accepting it. This is not always the case. Patient 12's head shave story illustrates immediacy between acceptance and avoidance.

‘When I first thought about [being bald], I'm like, ‘What? I can be okay with that. I see women on TV bald all the time.’ **But then when it actually happened, reality hit. I looked in the mirror and turned away. I looked ugly,** and then my daughter went in and shaved her head so that she would say, ‘**Look mom, you're not ugly. Am I ugly? I'm bald. You're beautiful.**’ **Then after that, it got okay**” (Patient 12\_2, p. 5).

The adult daughter shaving her head in solidarity helped shift her mother's mirror moment from avoidance, shock, and disappointment to one of disappointment and comfort, potentially leading to acceptance which could help the alopecia coping process and strengthen the mother-daughter relationship. Patient 12's mirror moment exemplifies how the personal is also relational. It calls attention to the emotional strain of accepting a reflection that does not parallel a patient's perception of self.

In contrast to Patient 12's emotional response to her reflection and similar patient responses featured in extant literature (see Redgrave et al., 2004), Patient 18 reported having a “non-reaction.”

“...And I, you know, came in the house after [the head shave in the yard] and **looked at myself in the mirror, and I was like, well, I guess that's what I look like, you know, without any hair.** I really wasn't, you know, **it didn't bring me to my knees or anything, I was just looking really, basically a non-reaction, I just kind of accepted it as okay, there we are**” (Patient 18\_1, pp. 1-2).

Patient 18's curiosity is natural. Immediately "kind of accepting it" and having a "non-reaction" were not common among interview participants. Instead, data indicate ovarian and uterine cancer patients were commonly surprised by their reflection, suggesting a sub-theme of "looking worse than I feel" within the mirror moment theme.

**Looking worse than I feel.** Some patients (17%) reported difficulty with mirrors because they looked sicker than they felt. This problem continued throughout chemotherapy and after chemotherapy while hair was slowly returning. Two patients who were in the first half of their chemotherapies describe:

"You have days when you're sick, there are days when you're burdened, days when you're bad and **some days are good. And you look at yourself and how sick you look.** You know, I never look sick, but **I look sick from my hair** because my hair was falling out and you see it and **you look in the mirror and you just start crying because you know you're sick...** So I mean, it was emotional but I could still go out in public and do stuff" (Patient 17\_1, p. 3).

"...My biggest reason is because if I see myself, I like to look good. And I can say to everybody it does matter, but **if I'm going through this and I go over and look at the mirror and I see somebody that doesn't have hair and I look sick, I will feel sick. I don't feel sick. I feel like I can do this**" (Patient 4\_2, p. 5).

Both narratives exemplify tension between an external image and an internal feeling. This tension contributes to patients' sense of self and state of being. The American Cancer Society's "Look good, feel better" (LGFB) Program ([lookgoodfeelbetter.org](http://lookgoodfeelbetter.org), 2012) targeting female cancer patients uses discourse to



reinforce the connection between self-confidence and appearance. The discursive frame of “Look good, feel better” is not useful to patients who say they feel good but look worse than they feel. An ovarian cancer patient explains:

“Anyway, I did it [head shave] and **it took me quite a while to look at myself in the mirror. I scared myself the first time** I saw myself. And eventually, I just decided that’s the way it’s going to be... For me, it took a week. For me, that’s a long time. I was already dwelling. **One time I saw myself, so I quit looking at myself in the mirror then it got easier. As I just got out of the shower I would walk away from the mirror.** That first chemo really did me in and I really look awful. **I really looked like death run over, and I think I scared myself.”**

Interviewer: Do you think how you appear impacts how you feel?

**“No, I looked worse than I felt”** (Patient 22\_1, p. 1).

The last statement in this excerpt is key. Because Patient 22 looked worse than she felt, she avoided looking. The “Look good, feel better” (LGFB) Program argues improving external appearance will result in feeling better, yet it does not parallel the experience of women like Patient 22 who avoid mirrors, yet when confronted with their reflection, recognize how much better they feel than their appearance suggests. For Patient 22’s experience to resonate, the LGFB Program’s motto would need to change to “Feel good, look better eventually” or “Feel good, avoid looking.” When asked about the LGFB Program, Patient 22 communicated disinterest, repeating throughout the experience of chemotherapy-induced alopecia that her appearance did not match how she felt.

Patient 22's approach to coping with mirror moments was to simply avoid the mirror. For others, it was more difficult. Mirror moments can lead a patient to feel worse than she did prior to looking into the mirror. Patient 23 explains:

"You have your doctor's appointment and they say, 'You're cancer-free right now.' You're going home and **you think I'm a healthy person again. And then you look in the mirror and still look like a sick person. And it's going to have an impact on getting well because you still look –you still come to face the face of the sick person every day, for a long time.** Even though you're cancer-free, you're still a cancer patient.

Interviewer: That's very well said...

"Definitely. And **I'll be looking like a cancer patient in my mind until I have a hairstyle**" (Patient 23\_1, p. 21).

Patient 23 anticipated the tension between internal feeling and external image would dissipate once her hair returned to a length long enough to style. Throughout treatment, Patient 23 resisted wigs, saying they were "false," choosing to wear scarves and soft caps always in public and almost always in her home in case a friend visited unannounced.

Patient 23's second interview took place after she completed chemotherapy. She continued wearing head coverings because "**you can still see my scalp and I just didn't like it when I looked in the mirror and I just didn't look like me**" (Patient 23\_2, p. 3).

As Patient 23 described how she made sense of her end-of-life stage, she continued to reference her changing appearance and the mirror.

Nearing the end of her life, Patient 23 reported still looking sick and was planning ways to change her image in an effort to lessen the gap between perception of self and the

mirror's reflection. She was not in pursuit of looking like she did before cancer. **“My whole image is going to change,”** she said. “I’m going to experiment with hair dye. Maybe blue! I’m doing things with my look I would’ve never done...but I have to fit ten years of hairstyles into one, she said.” Patient 23’s emphasis on post-chemo hairstyles speaks to Freedman’s (1994) argument for hair as a characteristic of personal choice and expression. Her plans are also an act of autonomy, communicating a willingness to improvise with an appearance that is forever altered, especially on days when she feels better than she looks. Unlike Patient 23 who was clear about having to make a serious effort to shift her perception of self when looking in the mirror, a small number of participants referenced their mirror moment as an experience that made them feel better about their state of illness.

**Looking better than I feel.** In contrast to the previous section discussing how the mirror’s reflections were perceived as worse than perceptions of self, two patients with recurrent ovarian cancer referenced unspecific moments of looking in the mirror and liking what they see. This was rare.

During her explanation of why dating is complicated for women who are going through CIA, Patient 20 said, **“I know when I look in the mirror all the time I say, oh, I don’t even look sick”** (Patient 20\_3, p. 7). She contextualized her statement describing how gender, sexual activity, and romantic involvement impacted how a patient manages her alopecia, which I address further in the “role of partner” section of this analysis. For the sake of this section, her reference to the mirror demonstrated a direct confrontation with her health status. Patient 20 was in stage IV of her recurring cancer. The first time we met she was terrified and, like most patients on the day of receiving devastating news,

did not care about her hair. Of course she did not. No one would. As she progressed through treatment, she continued to communicate confidence in her appearance.

The word “confidence” was almost never used in the data, and excerpts like the one from Patient 20’s interview were uncommon. How could Patient 20’s perception of self during chemotherapy differ so greatly than the majority? Simply stated, following the trajectory of chemotherapy treatment plans is critical. Patient 20 was moved off the drug that caused alopecia and experienced regrowth far earlier than most. This had a drastic impact on how she coped with chemotherapy.

Patient 19 also spoke about the mirror and its reflection as a way to reinforce confidence.

“If nobody ever said to [other female patients] wow you look good, then **when they look in the mirror, they never look at themselves and say, wow I look good. I still have men hitting on me.** That’s what I find amazing. I think, what? I’m old enough to be your mother” (Patient 19\_2, p. 4).

Patient 19’s career as a holistic esthetician better prepared her for mirror moments. She used phrases like “doing fabulous” and was adamant about the relationship between aesthetics, mindfulness, and quality-of-life. She connected self-affirmation to quality-of-life, saying patients’ frames of mind are influenced by “what they put out and what they take in.” She also acknowledged how exhausting this way of thinking and speaking was. “People ask how you’re doing, and you say, I’m doing fabulous. Fabulous darling. But sometimes, it’s just exhausting,” she shared. The multilayered responses Patient 19 shared during our interviews illustrate the complicated nature of responding to “why” and

“how” questions related to an aesthetic of illness. At times, patients’ responses were contradictory or changed over time.

Encouraging patients to reflect on past experiences with CIA in reference to present day provided insight into their process. For some, it was an evolution. For example, Patient 19 is also referenced in the upcoming sub-section, “shock and misrecognition.” Her excerpt above about having a positive association with the mirror is in reference to her current mind frame. When reflecting on past experiences related to CIA, Patient 19 said she was shocked and unprepared to confront her appearance.

**Shock and misrecognition.** The most common shared experience contributing to the mirror moment theme was one of shock and misrecognition. Of the total participants, 30% mentioned looking into the mirror and experiencing some form of disturbance explained as shock and/or misrecognition. My time spent in the cancer center’s hair salon observing head shaves and wig fittings contributed to my assumption that shock occurred during and immediately after the head shave or perhaps for a brief period of time during an adjustment phase. This is not the case. There are times when shock and misrecognition did not dissipate over time. For some, the shock of being bald and feeling unrecognizable was prolonged or postponed.

Patient 8 had difficulty recognizing her reflection immediately after the head shave and continued to feel this way over time.

“[The head shave] was on a Sunday morning and **I did not feel bad at all. I looked at it. I thought to myself, gee, I look like my father when he was balding. I put my scarf on it immediately. I didn’t want anybody to see me without the scarf.** The only person ever saw me was my daughter because she

would help me shower at that point. **But no one else ever saw**' (Patient 8\_2, p. 10).

Patient 8 made an unwavering commitment to wearing head coverings throughout chemotherapy. In the first phase of alopecia she had anxiety thinking she could be the statistical outlier whose hair never returned. The shock of being bald morphed into prolonged distress that reduced her quality-of-life.

Patient 16 was bald for months before experiencing shock and misrecognition related to her alopecia.

**'I look in the mirror and I laugh ... when I take this [soft cap] off...This is ridiculous I mean...**

Adult Daughter: Why? Why ridiculous?

**"I look in the mirror and say oh who's that ugly woman? I want to look more like my natural self"** (Patient 16\_3, p.2).

Patient 16 completed chemotherapy but was not "cancer free." During the third interview, Patient 16 described a slow transition from not caring about hair loss and rejecting the idea of wigs to wanting a wig and an appearance that "looked more natural." The mirror's reflection was used as evidence of their feelings. Patient 16 judged herself and her desire for a wig as "ridiculous." This excerpt highlights the difficulty of verbalizing concern for an aesthetic side effect that does not relate to surviving cancer. Recognizing your reflection as "ugly" or as other patients said, "looking terrible" or "looking like death" are feelings, so they are discounted as "ridiculous" in the context of life and death. This is the core of the problem. The grand narrative of cancer

(Mukherjee, 2010; Lerner, 2004) leaves little room to reflect on what quality-of-life looks like.

Patient 15 struggled to manage her alopecia. Looking into the mirror reminded her of death and dying.

“Because I look like, **I look like a chemo patient**, like, I want to say like the poor people that were, you know **the Holocaust survivors that’s what I feel like**, I feel like you know **they all lost their hair** because of the way they were treated, I just feel like that. **I feel like I look terrible. Like I’m going to die or something.**”

Interviewer: I’m sorry to hear that.

“...So I had [my hair cut short] right away. They did say that sometimes it’s easier to deal with it cut shorter, so that didn’t bother me too bad...but probably **when I’ve lost 70% of it, I looked in the mirror and then you just don’t see yourself anymore. You know you see somebody else looking back at you...It grew progressively sadder and sadder [laughter] but you know, you kind of know that’s what’s going to happen and even though you know that’s going to happen it’s still harder to deal with**” (Patient 15\_1, p. 4; p. 9).

Another patient with recurring ovarian cancer had a similar experience, saying she ‘blending in’ was not an issue until she reflected on her actual reflection in the mirror. Subsequently, she described her significant weight loss and hair loss as terrible and shocking.

“I somehow was optimistic that they said 90% chance your hair is going to fall out. Well, it was 100%...I had shoulder length hair. **It just kind of came out in**

**clumps and I didn't look at myself very much in the mirror and so like once I finally did, it was...It was terrible.** My husband didn't say how terrible it looked...He doesn't even pay attention which I guess is good but...we had a big boat at the time and we're out. I remember this. It's weird. We're out in the river in the boat like a 50-foot boat...I was out without a wig or anything on. **I just have these little chunks of hair and I didn't even realize I looked like that until I got home and I was getting ready to take a shower. You mean people were looking at me like this...**you know and they didn't have any reaction. They were strangers. They didn't want to gawk...(Patient 11\_2, pp. 9-10).

Some patients who shaved their heads shared a similar experience with Patient 11 where they do not realize the degree of their hair loss until they returned home and looked into the mirror.

**“It could be stressful, yeah. Because I remember standing in the line at the grocery store and some guy was looking at the back of my head and when I got home, I looked – we had a mirror with sides – I looked and there was this great big bald spot. And I said, oh my God, this is awful, and I felt really bad. But then the next day I said, okay we're going to do something about this”** (Patient 19\_2, p. 8).

For Patients 11 and 19, these mirror moments were the impetus for shaving their heads. The shock of being in private with one's reflection and realizing the image in the mirror was the object of unwanted attention is an example of how public and private experiences of CIA overlap.



By the time participants entered the early-middle phase of chemotherapy, it was an almost guarantee they were bald. Among the 17% whose “mirror moment” took place during the beginning phases of chemotherapy, Patient 14’s description was the strongest exemplar:

“I think a lot of this to do with identity. You can get used to seeing yourself in a way. **It is a shock when you look at yourself in the mirror and you have no hair. It's like you're looking at a different person.** I guess depending on your age and your amount of vanity that you have maybe or just how secure you are or whatever. It can be a difficult thing to deal with. **I thought I was pretty vain.** But I think I've lost a lot of that feeling [Laughs]” (Patient 14\_2, p. 8).

**Summary.** The “mirror moment” represents the personal, embodied elements of alopecia and how it was experienced in the privacy of patients’ homes. The “mirror moment” was discussed as a struggle that continued throughout chemotherapy and after, including remission/survival stages as well as recurrence and end-of-life. For some, the experience grew “progressively sadder” over time.

Participants often coped with the disconnect between external image and internal feeling by avoiding mirrors, while others confronted the mirror and did not recognize its reflection as their own. The mirror theme provided evidence to suggest the American Cancer Society’s “Look good, feel better” Program’s motto was not useful for patients who reported looking better than they felt. Unfortunately, the “Look good, feel better” Program is one of the only resources to which clinicians refer patients who have CIA-related concerns.

Some participants had difficulty communicating concern for an aesthetic side effect that did not relate to surviving cancer. This could be why patients used the mirror as a reference point to help explain the impact of alopecia on their everyday lives. For instance, Patient 22 entered and exited her shower differently to avoid the bathroom mirror, and Patient 10 covered her mirrors with towels. These mirror moment stories about small changes in behavior signify larger shifts in quality-of-life while living with alopecia.

One of the most telling illustrations of the difficulty in communicating concern for alopecia while enduring late-stage cancer was exemplified in Patient 16's third interview transcript (the excerpt was shared in the sub-section above). Her preferences changed from rejecting wigs to now wanting one. She qualified her interest in wigs as "ridiculous" yet said she looked in the mirror and wondered, "who is this ugly woman?" Following her story, how would wanting a wig to feel less "ugly" be "ridiculous?" Because sharing thoughts of feeling "ugly," or as other patients said, "looking terrible" or "looking like death," suggest a concern for appearance. By society's standards, such feelings should be discounted as "ridiculous" in the context of life and death. The grand narrative of cancer (Lerner, 2004; Mukherjee, 2010) leaves little room to reflect on what quality-of-life looks like.

The mirror moment reveals a shared experience that extends beyond preferences for head coverings, though head coverings remain an issue of importance. During CIA, the mirror's reflection and perception of self are in tension. External image and internal feeling impact quality-of-life in terms of sense of self and state of being. The subsequent

theme analyzes data pertaining to role taking. The roles of parent, career woman, and partner influenced how participants interpreted their hair loss and quality-of-life.

### **Theme 3: Performing Social Roles**

Chemotherapy is a brutal experience spanning months and sometimes years. One participant described it as “poison for your body.” Beyond the physical effects, one of the most trying aspects of enduring the side effects of chemotherapy over time was maintaining the social roles patients valued as part of their everyday lives. The social roles participants performed before chemotherapy influenced how patients experienced alopecia.

The theme of performing social roles was central to understanding how chemotherapy-induced alopecia (CIA) was enacted outside the clinic and how these roles contributed to patients’ quality-of-life. The analysis of the data identified the roles of parent, career woman, and partner as key components of how participants interpreted their hair loss and quality-of-life during chemotherapy.

Hair loss often hindered the role of mother/grandmother and the act of mothering. The role of partner and the role of mother/grandmother were hindered most drastically during the beginning and middle phases of chemotherapy. In contrast, CIA continued to impede the role of career woman throughout chemotherapy, including post-chemotherapy when hair was returning. Performing the role of partner was intimately connected with how patients manage their alopecia. The role of partner and women’s roles as parents were usually separate issues in patients’ stories.

**Performing the role of career woman: Bald in the workplace.** Of the total (n=23), 57% explicitly mentioned their work status and how it impacts managing

alopecia. Twenty-six percent explicitly mentioned retirement when explaining their decisions to wear coverings, and each devoted a large amount of time across interviews to explaining how not having hair would be more of an issue if they were still in the workplace. Two of those five women were adamantly opposed to wearing wigs because they no longer felt they had to wear a “sweaty” or “fake” wig to fit social standards. Patient 2 explains, “I’m retired now. **I’ve spent all the years I am going to try and impress bosses and peers and being perfect**” (Patient 2\_1, p. 2). Patient 2 associated autonomy with retirement, and referenced having more choices in deciding “who [she] wants to please” and “how [she] wants to look.”

The issue of class flows throughout this data set and dissertation, yet a thorough analysis of class and access is beyond the scope of this dissertation. Even so, it must be mentioned, especially when discussing work and employment in ways that imply participants have a choice in working when they might not. The phrasing of this sub-theme, “career woman” is used because most patients who mentioned work described their work life as a career. Current or former “career women” did not use more inclusive terms like “employee” or “worker” when explaining how being bald and appearing sick was a concern while they were in the workplace.

The demographic of this patient population is mainly middle class with the exception of a few patients’ stories that suggested low socioeconomic status. While Patient 12’s work status remains unclear, it is important to understand access to outstanding cancer treatment is not synonymous with access to resources in other areas of life, especially when discussing the social role of a career woman.

Some participants who were gainfully employed with jobs they enjoyed were “forced to retire” because cancer and its side effects became too taxing. Patient 5 continued to work until about halfway through chemotherapy. **“Even to work I wore [the wig] and they could not tell”** (Patient 5\_2, p. 4). Wigs were not part of Patient 5’s initial plan for how she was going to manage her alopecia. Partially because of work and her “love life” with her husband, wigs and hats became increasingly important. Patient 5 never left home without wearing a wig or hat.

I was visiting the cancer center’s hair salon when Patient 5 and her husband came in for an appointment to try on wigs. She was frail and in a wheelchair. This visit took place after the third or fourth time we had spoken but was in between our two formal interviews. Her voice was hoarse and difficult to understand, yet she declared, “I’m here to try on wigs. I’m open to a wig.” I could tell she used a fair amount of her already limited energy to make such an upbeat declaration. Perhaps she was able to muster the strength because of the familiarity of her surroundings. For over 20 years, Patient 5 worked as a cosmetologist. Unlike others who did not have exposure to wigs, Patient 5 explained how her work life made it both easier and more difficult to cope with hair loss. She comprehended the alopecia process better than most patients yet she also lost “what she does” by no longer being able to style her hair or work as a cosmetologist.

Some women who worked from home reiterated the opinions of those who were retired. For example, Patient 21 said, **“I used to be the type of person that wouldn’t leave my house without makeup or doing my hair. I was like that until I started working from home”** (Patient 21\_1, p. 11). Following the change in workplace and her diagnosis, Patient 21 left the house less frequently. When she did, it was never without a

wig, cap, or scarf, but her reasons were no longer related to work. If she still had to report to an office, Patient 21 said interacting with colleagues and customers would lead her to be more self-conscious about her baldness. Goffman (1963) explains patients' angst toward workplace interaction as a constant state of consciousness for others' awareness of an undesirable appearance that signals an undesirable illness.

Of the 57% who reported their career as having a role in their experience of hair loss, 30% reported working for profit throughout the entirety of chemotherapy. Of the total (n=23) 39% recounted specific examples of hair loss and appearance being an issue at work. Few reported receiving comments they perceived as supportive, and most shared stories of inappropriate stares or "strange" comments from co-workers like being "jealous" of weight loss or their hairstyle. Because of aesthetic-related side effects such as hair loss and weight loss or gain, some patients said co-workers had difficulty exchanging surface level greetings and would no longer make eye contact. Other stories included comments on wigs looking "real" when they "obviously were not" (i.e., having a short blonde wig when her hair was naturally long and brown).

Patients adjusted their roles in workplace relationships to accommodate chemotherapy-induced alopecia. For example, Patient 13 would not attend work meetings without a wig because being bald would distract colleagues from listening to her point. She describes:

**"The only time I'd go without the wig is going to the fitness center. I'll wear a scarf then. I'm a retired professor so I run into people and I just feel like I need to look professional. I have always thought I need to look professional...I have**

all these other things I can talk about and **[without the wig] the only thing they want to talk about [is cancer]**” (Patient 13\_2, p. 3)

In contrast, Patient 11 shared a retrospective story of support.

“...I was blessed with a really good career. Made a whole lot of money. I did what I loved...**I worked with people that I loved and they loved me...**But it was challenging to take the fork in the road after cancer because I was forced into retirement. **Without cancer, I'd still be working and stressed out and who knows**” (Patient 11\_2, p. 4).

Patient 11 retired before she lost her hair. The harsh reactions received by patients who endured alopecia while working do not parallel the experiences of those who kept their hair before leaving the workplace.

**Performing mother: The role of mother and grandmother.** The majority of participants (74%) were mothers or grandmothers. Mothering had a significant impact on how the majority experienced chemotherapy-induced alopecia. Patient 14, who lost her hair four times, compared enduring chemotherapy and alopecia to having children. **“I think I will never do this again, and then I forget about how horrible it was. Then I think, ‘You can do it again, one more time.’ So I keep doing it”** (Patient 14\_1, p. 3).

Relationships with children and grandchildren were usually sources of strength and struggle. Hair loss forced an explanation that some were not prepared to address, while others used their baldness as a conversational opening to discuss their illness. Four participants (17%) were mothers to children and young adults, ranging from 10-24 years of age. Eleven women (49%) discussed their grandchildren and their relationship influencing how they cope with alopecia and wearing head coverings.

There were specific moments after hair loss, around the early-middle phases of chemotherapy, when some children and young adult children withdrew from their mothers or grandmothers. Patients who experienced this unwanted shift in their relationships communicated deep sadness. These stories were among the most difficult for patients to articulate. The experience of Patient 5 exemplifies the hurtful repercussions hair loss can have on relational dynamics.

“There are some women who come in [to the salon where she worked] and are getting their hair done because they don’t feel well...they don’t get visited by their children very often, and they look sick. **I told my 20 year-old son I don’t ever see him [begins to cry]. He speaks five words [when he sees me].** But he sees [my husband] and talks to him (Patient 5\_2, p. 5).

Patient 5’s younger children were handling her illness better than the oldest. Mothering was one of Patient 5’s most valued roles, and she tried to prepare the family for her changing appearance.

“I explained to the kids that [my hair] is on its way out. **I showed them [my bald spots] and said if they had any questions to not be scared and if they want to touch it they can.** They all just laughed and said I was weird. I thought, nah, I’m hitting a nerve here...”(Patient 5\_1, p. 4).

A few grandmothers said they had hair loss conversations similar to the one above, but Patient 5 was the only mother who shared having one. Patient 14 staged a hair loss conversation by asking her grandchild to pick out her favorite wigs.

“I have a granddaughter who’s ten now. She was only four when this started. **I was concerned. I wondered how she was going to take this. I would wear a**



wig. Another time [recurrence], I let her tell me which wig was her favorite. **I told her I have a sickness and my hair fell out but it was going to come back. She helped me...**I don't know if a boy would be the same. **If you let them participate and make it not depressing...**I think they are resilient" (Patient 14\_2, p. 12).

Conversations with young adults are difficult partially because the patient knows the grandchild is aware of the meaning behind chemotherapy and hair loss. Cancer is pervasive. While the patient might be the first relative of the child/young adult to undergo chemotherapy and alopecia, different forms of media have featured cancer patients and characters who die from cancer.

Grandmother to an 18 year old, Patient 1 redirected hair loss conversations away from the subject, reassuring him "nothing's going to happen."

**"My grandson is suffering.** It's giving him a hard time. **He's not used to seeing me sick. He took a different route home school yesterday [starts crying].** He's very close to us. **I told him this morning, everything's fine and I'm strong.** Nothing's going to happen [husband and adult daughter start crying].

Adult Daughter: He had a meltdown. His grades are suffering because he's stressed. He started crying and went to the principal's office, and my son's a bodybuilder, taekwondo type.

Interviewer: I am so sorry. That's a hard age for this. What do you think was the tipping point for him?

**When my hair came out.** His school is next to our house. He checks in every day and **he didn't come visit for two days.** I figured it out. **That was after my hair fell out...**"(Patient 1\_2, pp. 3-5).

Recognizing shifts in close relationships such as those among parents and children could harm the patient's ability to progress through chemotherapy. In preparing for chemotherapy, Patient 6 shared distress over how her adult children and grandchildren would react and how their potential reactions determined her decision to shop for a wig.

"I don't know how painful or uncomfortable wearing a wig is. I don't know if it hurts...I mean, **it's like what I said to the kids last night. I need hair. I am not a beautiful woman.** I have not...[starts crying] I can't look phenomenal and have a shaved head. That's not me. It's not going to work, so **either I have a wig or I have some kind of scarf that is going to at least make me feel like I look less like a freak. I don't want my kids to go, 'Oh my God, Mom.'** I don't want them to see my head...I don't know how resilient kids are. I don't know" (Patient 6\_1, p. 5).

The anticipation of "looking like a freak" was reflected in Patient 4's description of an emotionally taxing memory when her child said her appearance was scary. Patient 4 did not complete chemotherapy. When asked why, she shared the following:

"[Chemotherapy] got harder. In my last chemotherapy I lost all my eyelashes...**When I lost my eyelashes, that's when I thought, I'm not going to do this anymore.** One time I had to dress my daughter for school. **She didn't know because I always have fake eyelashes, and I forgot. She said, 'Mommy, what's wrong with you?'** I said I did it on purpose, but this [signaled] a big

change. It was a big, big difference. **She even told me, ‘You scare me.’ It was hard**” (Patient 4\_3, p. 2).

As the mother of elementary school age children, Patient 4 said one of her main responsibilities as a mother was to maintain a sense of normalcy for herself and for her children. The surprise questions from her daughter and being told she looked “scary” was emotionally damaging, especially after altering her daily routine to include applying false eyelashes before waking her children.

Those who elaborated on performing the role of mother to adult children did so because the relationships were contentions. These experiences were rare. When adult children were mentioned, it was usually reiterating how they enjoy their friendship or in connection with stories about being a grandparent. Adult children frequently accompanied patients to appointments. When they did, patients almost always voiced their appreciation, saying general statements about feeling supported.

Patient 16 was the only participant who attributed her high quality-of-life (5 out of 5, spanning all three interviews) to her daughter. During the third interview, she said it was her daughter and grandchildren, but the previous times were directed only to the daughter. “I’m a 5 out of 5...why? Because of my daughter”(Patient 16\_1, p. 2). With the exception of Patient 3 who attributed her “5 out of 5” quality-of-life to God, no one else provided such succinct associations pinpointing one source of gratification above any else.

In contrast, some patients were able to draw direct associations between their relationships with adult children and stress related to wearing wigs. Patient 2 clarifies:

‘My daughter inherited some vanity I used to have, and **I think she’s worried about me going out in public and not being confident about who I am...That’s probably why she bought me a wig...**She’ll come to our house and say, ‘let’s take a girls afternoon and find your wig again.’ I’m going to say, ‘No, if you’re embarrassed by me and want to go someplace, I’ll put on a baseball cap.’ **I don’t want to invoke aggravation.** I don’t want that sweaty thing sitting on my head and having to make sure it’s sitting right up there” (Patient 2\_1, p. 3).

The description above is a brief exemplar of a longer, more complicated conflict between mother and daughter. The wig and wearing the wig remained a serious point of contention throughout the four interviews. By the fourth interview, Patient 2 was seeing a therapist to help address the conflict. The role of grandmother overlaps onto the mother-daughter relationship, demonstrating how the topic of baldness can signify a longer lasting problem of concern.

‘My daughter’s [reason for buying a wig] could be because **she doesn’t want the grandkids to see me bald.** They lost their other grandmother two years ago...a lot of her anger is **when we say cancer, to her, I am already dead and gone**” (Patient 2\_1, p. 4).

Most relational conflict between adult child and parent concerning wearing wigs did not have roots as deep as that of Patient 2 and her daughter. For example, Patient 12 was only one of two patients who were almost always bald in private and public spaces. The other participant, Patient 3, was the mother of younger teenagers and did not mention her role as a mother as influencing her alopecia experience. Patient 12, however, had an adult son who insisted on buying a wig “because my daughters told him that I said I was

ugly [starts crying]” (Patient 12\_2, p. 19). The purchase was perceived as a thoughtful gesture, but Patient 12 never wore it for herself.

“This morning, he and my daughter-in-law drove me [to the clinic] so I had the wig on. **If I took it off when he wasn’t there, my daughter-in-law would go back, saying, ‘your mother takes that wig off as soon as you’re not around.’** So I waited until after I had my blood drawn and got back here [in the clinic]. **I didn’t want her to come back** saying ‘Oh I forgot something.’ I’m like, ‘Okay I’m taking this off [laughs]. It has tiny combs that hit the back of my neck and dig into me” (Patient 12\_1, pp. 26-27).

For the majority of the interview, Patient 12 held the wig in her lap. It was as if she was prepared for her son and daughter-in-law to burst into the closed consultation room and demand proof of her wig wearing. For Patient 12, the wig became a symbol of self-sacrifice, paralleling the selfless and uncomfortable performance most grandmothers and mothers already enact long before chemotherapy-induced alopecia.

Three patients did not have children and three patients did not specify whether they did or not, making 26% of the total patient population under analysis. One of these six women mentioned mothering, saying she might have handled hair loss differently if she was a mother. She explains, **“My situation might be different if I had children, maybe. To look more like myself for them so they wouldn’t be sad.** But me not having children...I would have done everything [regarding hair loss] the same” (Patient 10\_2, p. 9).

The remaining five did not mention mothering unless it was in reference to their mother or grandmother or themselves as a child. For example, Patient 22 discussed how the challenges of her childhood prepared her for cancer and its side effects.

“[My cancer] was one of those sneaky things...It was a death sentence and I had to deal with it. I have an explanation for my attitude. I was a child growing up during the war in France...My family was almost killed...**I will always remember my parents saying, ‘don’t cry for anything. Save your tears for later. You’ll need them.’** You have to keep quiet. This was part of my upbringing” (Patient 22\_2, p. 3).

This patient’s motivation for caps was for functionality (e.g., to keep warm) and to appease her friends who would spend too much time talking about her baldness. In seventeen pages of transcript data, Patient 22 made mention of family, childhood/children, or parenting only once, which is featured in the above excerpt. Patient 22 did, however, spend time explaining her role as a wife and a widow, making sure I understood how the role of widow influenced her perception of hair as unimportant.

Similar to Patient 22, Patient 23 did not mention children or mothering, except for once when she mentioned the difference between herself and her grandmother.

“I know **my grandmother, oh my God. She probably would have refused chemo rather than lose her hair** and I know people who have actually done that. [Hair] was everything to her. And to keep her husband happy and attracted. She lives for him. She didn’t have an identity of her own” (Patient 23\_2, p. 12).

This excerpt is more about the role of partner than the role of mother. The two roles overlapped less than expected before the analysis was performed. The motivation behind managing alopecia rarely exists as one, family-orientated performance where spouse and mother are interchangeable roles. That is not the case. Patients perceive their baldness as signaling a similar message to spouse and child (i.e., “mommy is sick/grandma is sick;” “your partner is seriously ill/might die”), but the patient experiences the role of bald partner and the role of bald mother in different relational contexts.

Patient 18 described the difference in how she approached her marriage and her mothering.

“If my husband were still alive, I know **he wouldn’t care if I was bald**, but I’m wondering...**I’m trying to think how my kids, if they had been little**, how I would’ve reacted and **how I would’ve handled that...I can see myself saying, mommy’s bald and that’s why [I have no hair]**” (Patient 18\_2, p. 22).

The spousal relationship seems to be matter-of-fact and accepting, while the role of mother would require more strategic communication. Ultimately, Patient 18 would use similarly candid communication with her children, but she did not mention them “not caring” about her appearance in the same way she suspected her husband would not.

**The role of partner: Perceptions of intimacy.** The relational dynamics of hair loss has not garnered enough attention in extant literature. Some of the most salient descriptions of experiencing hair loss are from patients’ stories about fulfilling the role of partner. Sixty-one percent of participants were in committed relationships, including partnerships, unions, and marriages while interviews were conducted. Including those who were widowed and were divorced, 91% had experience performing the role of

partner. With the exception of one participant, those who were widowed said with certainty they would have greater difficulty losing their hair if their husbands were still living.

The role of partner was described as one of the most intimate, having a strong connection with how ovarian and uterine cancer patients make sense of their changing appearance and what it signals to those patients love. For example, the decision to purchase a head covering can be motivated by wanting to feel physically wanted. Patient 5 explained:

**‘I feel very undesirable without my hair...in my love life** [starts crying]...

Husband: It did hurt her

**‘That’s why we got a wig** and it made me feel a lot better, but as often as I wear a wig, **my hair is still a wig**’ (Patient 5\_2, p. 4)

Her hair “still being a wig” implies Patient 5 remains uncomfortable wearing a wig. Most participants who wore wigs shared similar opinions, saying they were physically and emotionally difficult to wear. I observed multiple wig fittings during my time in the cancer center’s salon, including a session with Patient 5. Friends were more vocal during appointments than partners. Partners showed more nonverbal support, where partners would react to patients’ body language to help set the tone of the appointment. Physical touch was rare between patients and their partners or their friends. This is not surprising when considering the wig stylist is already touching the patient’s head a lot more than someone with hair might contemplate. Many patients said it was an odd feeling to go from having hair to being bald and having someone touching their scalp.



The decision to purchase head coverings differs from deciding when and how to wear them. It is common for patients to cover their heads while they sleep to maintain a warmer body temperature. Both Patients 7 and 15 wore head covering to sleep for reasons unrelated to warmth and more related to their partnerships.

**‘I wear a tube thing at night to sleep. I don’t like him to see me bald. It’s what people wear when they’re fishing. I told you about it last time. He doesn’t like it for some reason, but...**

Husband: I rather [her head] be naked

No, **I’m self-conscious about it.** My scalp is pale” (Patient 7\_3, pp. 5-6).

“When I didn’t have any hair at all, **I wouldn’t let [my partner] see me without any hair. I would even wear a little cap at night when I was sleeping.** Of course it would fall off during the night [laughs] so I’m sure he saw me many times without it, but I just didn’t feel comfortable without it” (Patient 15\_3, p. 4).

Both of the excerpts above were from third-round interviews, supporting the argument hair loss continued to interfere with patients’ relationships over the course of chemotherapy. Some elements of the experience do not improve over time. During the first interview before her hair loss, Patient 15 said the image of her bald head “could get burned in your brain” and she wanted to avoid allowing her partner to have such an image. She later shared relief for already being in committed relationship, saying, “If I wasn’t in a relationship already and I was trying to date, **I would not date without hair. I just wouldn’t. I would feel so unattractive without my hair**” (Patient 15\_3, p. 5).

Longitudinal, compassionate interviewing (see Ellis & Patti, 2014) laid a conversational foundation for patients to share stories of self-consciousness and intimate moments throughout their hair loss. Because we were discussing a “softer side effect” of chemotherapy as opposed a side effect less gendered and socially visible, women took the time to share how they think their partners see them with cancer and without hair. A common thread among those who spoke about their partnerships and hair loss was the issue of security.

“My appearance used to be a big concern. It isn’t now. Every hair, it had to be in the right place. The makeup had to be just right. [Because of my relationship] **I don’t have to trap anybody to take care of me**...sex itself is not an issue. Yes, I enjoy it but it’s not something at this stage. Right now, I don’t have the energy for it and with all the crap going on down here [e.g., colostomy bag, surgical healing], sex is something I don’t want to consider...**but [I feel] settled and secure**” (Patient 2\_4, pp. 9-10).

The patient population under examination has, for the most part, committed to enduring chemotherapy and its side effects. For some, the effects are unknown and for others in recurrence, effects such as hair loss are less startling. The women who communicated associated their committed relationship with feeling better about being bald might connect with the idea of a double commitment, where the partnership and the chemotherapy overlap. Patient 6 explained:

“My husband...you know I just wanted to know...**what do women and men do when they’re alone?** I mean, I don’t even need to push on the ice machine to get a glass of water because **he’s taking care of everything** (Patient 6\_1, p. 2).

The idea of being “taken care of” was unsettling to Patient 6 and Patient 5 because they identified as the caretakers of their families. Patient 6 “loved to clean” and Patient 5 enjoyed planning and executing family activities. The role reversal of caretaker was subtle and difficult for some participants. Beyond the role of caretaker, Patient 5 valued the feminine role she played in parts of her marriage.

“This is something I would not necessarily share, but [my husband] is very sweet to me and **he makes me feel wanted...**because **I think all girls like to feel they are wanted. That’s why I bought the wig**” (Patient 5\_2, p. 11).

The support of “feeling wanted” did not resonate with other patients who performed partner in a friendlier manner. For example, Patient 9 and her husband “got matching head shaves” and joked about needing my hair. In the second interview, she shared annoyance with her husband’s attitude toward her needing a hat.

“Why do I wear hats? Because **my husband is always telling me** the hair on the back of my head is sticking out and **to go put a hat on**” (Patient 9\_2, p.2)

Interviewer: So if it wasn’t for that would you go completely without hats or head coverings now that it’s growing back?

“**Probably...**I’m incredibly fatigued” (Patient 9\_2, p.2)

The slight criticism and banter between Patient 9 and her husband seemed to be a way of coping with the serious change in their lives together. The first interview transcript was sprinkled with banter and appeared to serve as distraction. The commanding tone Patient 9’s husband used regarding a head covering differs from the tone communicated in Patient 17’s account.

**‘I basically started wearing a wig when my husband told me I got a big bald spot on the back of my scalp...My husband’s balding on the top of his head...he said, ‘It’s really starting to get noticeable in the back...I still had hair but I started wearing a wig...it just kept coming out’ (Patient 17\_1, p. 13).**

Her husband’s balding head seemed to make him more aware of how noticeable her bald spot was. The underlying message of Patient 17’s story about wearing wigs was she made the decision, but the decision was easier because of her husband’s communication. The two references to him and the multiple uses of ‘I’ suggest shared decision-making. The mutuality made more sense in the second interview when Patient 17 mentioned she and her husband work together and are “around each other 24 hours a day.”

**Summary.** Performing the roles of mother, career women, and partner impacted how participants experienced alopecia. While patients are visiting the gynecologic oncology clinic, the roles of mother, career women, and partner exist on the periphery, as they are not the center of attention during a medical exam, for example. Outside the clinic, these social roles remain key contributors for how patients interpret their experience of CIA. When asked, “how do you define quality-of-life,” many participants mentioned mothering, their career, and/or their relationship with their spouse/partner. Because alopecia impacted the performance of these three roles, it also impacted participants’ quality-of-life.

Patients who mentioned the role of career woman identified it as central to how they managed alopecia. Data demonstrated the difficulties of workplace interaction, including a heightened self-awareness pertaining to wearing wigs, which was done to

reduce the chance for unsolicited conversations with colleagues about hair loss and cancer. Those who were retired said they would be more bothered by CIA if were still reporting to their place of work and interacting with colleagues.

The role of partner was the most complicated of the three because it was the most intimate and included feelings of security and feelings of self-doubt related to alopecia. For example, patients reported feeling undesirable after hair loss, some not allowing their husbands to see them bald and wanting to sleep in wigs. These same conversations featured stories of feeling secure and supported. Patient 2 explained the aspect of security, saying, "I don't have to trap anybody to take care of me" (Patient 2\_4, p. 9). Security in their marriage (commitment) was strongly associated with feeling secure in their altered appearance. Almost all who were widowed said managing alopecia would be of greater importance if their husbands were still alive because they would want to appear attractive.

Mothering was an active role most participants discussed in reference to their quality-of-life. Grandmothers and mothers to children and young adults often reported their alopecia as having a negative impact of their relationships. Some children and young adults withdrew from these relationships, creating emotional distance by physically avoiding patients or not talking when they were around each other. This was a source of additional distress for participants who were able to locate the shift in behavior as taking place after they lost their hair.

The language used to discuss chemotherapy-induced alopecia was gendered, especially when patients spoke about social interaction. Everyday errands, for example, became an instance of becoming visible to the public eye. Patients were aware of being

noticed by strangers as a woman with cancer, and it impacted their willingness to leave the privacy of their home. Functioning in public was an experience of “gendered visibility,” and is the next section of analysis.

#### **Theme 4: Gendered Visibility**

The analysis of the data revealed ovarian and uterine cancer patients had a high level of concern toward being perceived in public as a cancer patient. Alopecia was the top reason for being recognized as having cancer, and being recognized was contingent on patients’ gender. Almost all participants repeatedly spoke about the gendered elements of CIA and how difficult it was for them to blend in because their appearance went against social norms.

Participants acknowledged American culture at large as more accepting of different appearances than in the past. They also said cancer was steadily becoming more prevalent in today’s society, resulting in most people knowing someone who has endured chemotherapy. Social progress specific to alopecia was rare, with most patients’ experiencing CIA as a gendered binary. Patients compared their experience of CIA in public to men’s, arguing women with bald heads or scarves/caps were recognized as cancer patients because they were women.

Data led to the development of the theme, “gendered visibility.” The theme emerged from data represented by numerous axial codes such as privacy, stigma, gender, recognized, control and loss of control, and treatment in public. For some, being recognized was an issue because they wanted more control over who knew their health status. Others were less concerned with strangers knowing their health status but adamantly against being approached by people who had questions or stories about cancer.

Whether viewed as a breach of privacy or not, increased visibility impacted patients who valued social interaction as part of their QoL.

Described with precision, Patient 21 stated, **“Your head is speaking for you.”** The “you” in this statement was not universal, and Patient 21 did not suggest it was. The “you” Patient 21 was referencing applies to women, particularly in a society with Western values and expectations such as the one where this research took place. Both Patient 21 and her husband have had cancer. Both are bald. And yet, he was not approached by strangers asking, “what kind of cancer do you have?” Years after treatment, her husband remains “bald by choice” (Patient 21\_1, p. 9).

**“When he started coming [to the cancer center] as a patient, he commented, ‘I don’t want people to think that I’m bald because I’m having chemo.**

**They’ll think I’m sick...I don’t want people to think...’and I’m like, ‘they would never think that. They wouldn’t have a clue.’ He finally got it...”**(Patient 21\_1, p. 9).

The husband knew what a bald head in a cancer center communicated. Patient 21’s reassurance could not be reciprocated because it would be disingenuous. The difference between the husband’s angst and Patient 21’s is hers is not reserved for the cancer center. She explains:

**I will not go anywhere without a hat. I feel bare. Even seeing the doctor, I leave my hat on...I would not go to the store. I would not go pump gas. [If] I forget my hat, I’ll turn the car around and go home”** (Patient 21\_1, p. 6).

Her husband's awareness of the public's perception and Patient 21 feeling compelled to return home when forgetting a hat are evidence of the worry CIA can add to an already taxing situation.

Some patients' husbands who were not sick and were "bald by choice" or naturally balding compared their appearance to patients' in an effort to connect. A frustrating exchange took place between Patient 17 and her husband who was naturally balding when he stated, "hey, I'm bald too." Patient 15 experienced similar frustrations with a partner who was bald. "He'd say, I understand. I get it. A couple weeks ago, I exploded on him because he doesn't understand...this is chronic" (Patient 15\_1, p. 5). These types of conversations did not ease the distress patients felt toward their appearance. Patients noted the shock of the rather speedy timeframe in which they lost their hair and compared to their partners' years of natural progression toward balding. The shock Patients 17 and 15 referenced was more personal than social, though the two are intertwined. Being personally shocked by the drastic change in the appearance was analyzed in "the mirror moment" theme. Uncomfortable reactions from strangers were a social experience that relied on socially constructed, gendered standards of appearance. Patient 5 makes a gendered comparison to explain this.

"It's hard for some people because **hair is part of your identity. But I think it's easier for men because if you shave your head, it's not shocking.** You know, **as far as a woman with no hair, it's a little bit more shocking to society.** But I think you sort of have to get the right mindset..."(Patient 5\_1, p. 7).

Data established a communicative pattern of comparable aesthetics, where ovarian and uterine cancer patients enduring alopecia differentiated their experience of



alopecia to that of men and also compared their “gendered visibility” to other women with cancer. Patient 14 demonstrated this in the following excerpt:

**“I see other patients here and compare myself to how they look. I think, gee I look better than I thought! I see women in the [hospital] lobby walking around with bald heads and [they] look really sick. I don’t look as bad as they do”** (Patient 14\_1, p. 1).

Ovarian and uterine cancer patients spend significant amounts of time in the clinic. From an interpersonal communication perspective, it is natural to compare appearances and establish an informal order to interpret one’s surroundings and position as a patient (see D’hont, 2002; Goffman, 1963). Jorgenson and Steier’s (2013) argument for “lower order frames” suggests patients use the social norms of the physical environment to construct “higher order meanings.” In this case, the lower order frame is the clinic’s lobby, signaling to those who are in the space that all are there for treatment or to support those in treatment. Higher order meanings are constructed based on how patients see themselves, how they see other female patients, and how they think other female patients should look.

Some patients’ perceptions of being bald in the public sphere went beyond Patient 14’s comparison, making gendered claims of value concerning other women’s appearances and head covering choices. The following two are exemplars.

**“I wonder about women [who don’t wear wigs]. Do they want the attention? Do they like sympathy? Why are they doing that? But of course, I never ask”** (Patient 11\_1, p. 3).

**‘I can’t figure out why some [women] go around looking as ugly as possible [without head coverings]. I mean, certainly we are going through some ugly stuff so why look ugly?’** (Patient 19\_2, p. 3)

These statements reflect social norms and expectations about how women are supposed to handle their alopecia. Extant research provided a foundational understanding of how social norms influence experiences of chemotherapy-induced alopecia (Choi et al., 2014, Freedman, 1994, Frith et al., 2007; Hansen, 2007; Rosman, 2004), yet the problem of relational communication among women with CIA has not been addressed except in ways that showed evidence of only positive support (Koszalinski & Williams, 2012). The excerpts above feature patients’ judgmental interpretations of other women with cancer. This humanized the image of cancer patients who were not always lone warriors (Lerner, 2004) who do not pass judgment and were only concerned with survival. Some women with cancer superimposed their best practices for how other women with cancer should manage alopecia.

The clinical environment of the cancer center does not negate the effects of gendered expectations. Being bald in the clinic *is* being bald in society. For example, Patient 5 commented, **“There was a time when I was coming to [the clinic] and forgot my hat. I was really upset so [my husband] stopped and bought me a hat”** (Patient 5\_2, p. 12). Head coverings are often perceived as an issue for women by women. Patient 5 did not differentiate the expectations of the clinic from other public spaces. Other patients reiterated Patient 5’s perspective and attributed the pressure to cover (see Yoshino, 2006) to wanting to appear attractive. Patient 23 described how this is gendered.

**“[Hair is] important for women to be sexually attractive.** I’m not trying to attract the opposite sex. I’ve had bad relationships in the past, and I’m just done with it. [Hair loss] is more for the opposite sex and for sex life. **It’s not an internal type of thing. A lot of women are out to find their partner when they’re older too...**you’re just not trying to nest” (Patient 23\_1, p. 12).

The value of women’s hair is historically situated and dependent on culture values (Freedman, 1994; Hansen, 2007). Almost all participants (96%) described CIA in gendered terms. During her explanation of alopecia being a women’s issue, Patient 23 compared having hair to having breasts.

**“[Having hair] is just like having breasts...it is important in a sexually attractive sense...like women who’ve done breast reconstruction after mastectomy.** I think if that was important to your life early in life, it’s still going to be later in life” (Patient 23\_1, p. 13).

The excerpt suggested appearing sexually attractive was synonymous with appearing womanly in American society. Considering the average age of participants was 62 years and 91% identified as straight/heterosexual, it was unsurprising that these data reflected heteronormative standards. It was also unsurprising because heteronormative standards are the standards of American society where this research took place. Patient 6 described her hair regrowth as “looking dykey.” One of Patient 10’s top concerns related to hair loss was being perceived as gay. “Not that there’s anything wrong with it, but I live in a very gay community and I know people are going to think I’m a lesbian.” Patient 15 reflected Patient 10’s concerns, but in a less serious sense.

“I haven’t been going out in public much without [my wig], but **I’m trying not to go back to the wig** unless there is a wedding. I think people’s problem with me right now is, **‘yeah, she’s probably recovering from cancer treatment’ or they think I’m a gay woman that shaves her hair** [laughs]” (Patient 15\_3, p. 9).

As discussed in the “performing social roles” theme section, the issue of attractiveness and desirability was closely connected to marriage. Patient 16, who was in her 80’s, attributed women’s marital status to managing alopecia. She also turned the questions back to the interviewer, which is an example of how control over the direction of interviews was not unilateral<sup>2</sup>.

**“It probably has something to do with vanity. I mean, you have beautiful hair, wouldn’t you be vain about it?”**

Interviewer: Oh, I’m pretty vain about it. Yes, I am. It would be devastating.

**“Are you married?”**

Interviewer: No.

**“So you’re looking. So the hair means a lot too. Because [my hair] doesn’t matter to me now that I’m single. I’ve been widowed for sixteen years”**

(Patient 16\_1, p. 2).

Because hair grows at such a slow rate, the aesthetic of chemotherapy-induced alopecia lasts far longer than chemotherapy. Patient 16’s statement suggests “still looking” to date and “looking like a cancer patient” exist in opposition, regardless of health status.

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<sup>2</sup> Refer to Golombisky (2006) for a detailed analysis of shifting power dynamics during interviews.

Gendered visibility extended beyond becoming visible to other women or men. It applied to moments when children recognized the difference in a patient's appearance in comparison to other adults. Patients used these stories to explain the heightened visibility they experienced. Excerpts from Patients 1 and 3 serve as examples.

“[I’m recognized in public] **by kids mostly...they will look at me, then look at me again. I give them a wink and smile** and that throws them off a little bit.

They don’t want to look back and check [me] out. At least I’m trying to let them know its okay” (Patient 2\_4, p. 5).

“**Kids are always looking, asking themselves ‘what happened to this lady?’**

In church or the grocery store, they look. And it’s not a judgmental look. It is just questioning, like what happened? Other people look, like, ‘oh poor lady.’ **I keep smiling and talking and acting full of life, and they realize I am good. People don’t have to be scared**” (Patient 3\_1, p. 4).

Young children were not perceived as accountable for their actions in the ways adults were. Patients intervened in easing children’s processing of their appearances, adding to the burden of functioning in public. Most participants who shared moments of visibility between themselves and children did so to demonstrate their awareness of others noticing them (see Goffman, 1963). Patient 18 describes her appearance as a “stunner” for children:

“Once in a while, I would be out in public like in a store and there’d be **a little kid walking on their own, maybe four or so, and they would catch me with my hat on** and you could tell they were trying to process why I was wearing this

thing. **If [I] were bald, I'm sure the four year old would've gotten –I've gotten even more demonstrative reactions because you see bald men but you don't see bald women walking around very much. I would've been a huge curiosity.** A kind of stunner for a small person” (Patient 18\_2, p. 7).

As demonstrated earlier, a female patient's experience of becoming visible was explained in contrast to a man's. There was no actual man with chemotherapy-induced alopecia in this encounter, yet Patient 18 was confident in her juxtaposition. Her confidence in children being comfortable seeing a bald man as opposed to a bald woman was rooted in stigmatizing norms she has personally endured for the sake of maintaining social order (Rosman, 2004).

Among the most frequent reasons for wearing head coverings in public was the desire to “blend in” among strangers without being recognized as having cancer. Patient 14's appearance made her hyperaware of employees' reactions at stores she regularly visited.

**“When I went to the supermarket and didn't have a wig on the employees would come and offer their help [laughter]. I would say, ‘is it really that obvious? One time, I was leaving Walgreens, and they said, ‘Be Well.’ And I thought, ‘Do I really look that bad?’ I asked, and they said no, it was a new policy to say that to everybody [laughs]. I said, tell your manager it's ridiculous”** (Patient 14\_2, p. 10).

Patient 14 mentioned the employee's “be well” farewell during both interviews. The “be well” moment signified Patient 14 dividing her lived experience into stages of “before alopecia” and “after alopecia.” Before, she was able to blend in and regularly function

without thinking strangers were staring. The noticeable change in attention led to an increase in self-consciousness. She attributed moments like this to her reasoning for wearing a wig in public more often than she wanted. According to Patient 14, the physical discomfort of a wig was worth the feeling of blending.

Rosman's (2004) research on CIA and stigma argued head coverings such as wigs, scarves, and caps function as "camouflage." Yeager and Olsen's (2011) research on scalp cooling and alopecia used the same phrasing to present their work. Though one of this study's participants used the word "disguise" in reference to wearing a wig and others described wigs as "fake," none of the patients responded positively to the question of whether they thought head coverings were different forms of camouflage. Even the patient who said her wig was a "disguise" contradicted her statement when asked the question about wigs as camouflage.

**"I like to blend in...I always disguised myself.** I never ever went out without my wig and **when my hair was like an half inch long, I rarely wore hats and kept wearing my wig** except one time when I went out to a bar with my niece...the only thing I was missing then was a nose ring and a tattoo (Patient 11\_2, pp. 7-8).

Patient 11's cancer journey has spanned fifteen years. As a self-described "tomboy" (Patient 11\_2, p. 14), wearing wigs was not an act of femininity but an act of blending. Having hair allowed her to blend in to a society that expects women to have hair. When a patient's identity is inextricably linked to blending into society, it is highly likely that patient will then place a high value on head coverings, especially wigs, regardless of perceived femininity.

For those like Patient 11, wearing a wig is not about looking good to feel better. Rather, it is about complying with socially constructed norms to which she does not object. It is about blending in for the purpose of not being bothered.

**‘I don’t consider the wig camouflage. I just want to be normal and not draw attention to myself.** I don’t run out with a bald head because I don’t want sympathy. **I don’t want people giving me advice.** Everybody wants to say, ‘oh, there’s a fantastic cure for cancer,’ and I’ve heard all of those comments. I just want to get through things normally and the wig makes me normal...**I’m not trying to hide the fact that I have cancer, but I don’t want strangers who don’t know me barging into my life.** I’m very much a private person” (Patient 11\_2, p. 9)

As the conversation continued, we discussed the topic of taking a stance against blending into the norm by “going bald” in public. I summarized Lorde’s (2009) call to action for women with cancer to reject wigs and be bald in public for the political purpose of challenging patriarchal norms. Lorde’s (2009) approach to alopecia was discussed with multiple patients. Each time, it failed to resonate. When asked why, responses were reflective of Patient 11’s, saying, **“you know, I don’t have the energy for –I do kind of protest some things, but this I just can’t. I personally can’t do that”** (Patient 11\_2, p. 13).

An analysis of patients’ perceptions argues against Rosman’s (2004) and Yeager and Olsen’s (2011) concept of head coverings as “camouflage.” It was too harsh. Camouflaging was a linguistic frame that structures the expectation for wigs and caps to effectively conceal alopecia (Tannen, 1993; Tannen & Wallat, 1982). This could



dishearten a patient who continued to feel exposed while wearing a wig, cap, or scarf, perhaps perceiving her efforts as ineffective. It can also miss the actual meaning of a patient's actions, as demonstrated by Patient 13 who wears wigs to avoid conversations.

**“I hesitate a little bit with the idea of camouflage because I don’t mind people knowing that I’m sick** but I don’t want to have to talk about it all the time when **I have other things I need to get done.** It’s not that I’m trying to hide something...**I don’t want to divert people’s attention from why I’m [visiting their place of business]**” (Patient 13\_2, p. 6)

For Patient 13, the wig is worn to signal a desire to be left alone, which was not an attempt to camouflage her health status. She was not invested in caring whether a stranger thinks her wig was real hair or not. The wig might have communicated her health status of “cancer patient,” but she believed it signals “cancer patient making an effort to blend in” which, in turn, achieved her goal of being left alone in public spaces.

Camouflaging alopecia implies a degree of success in concealing one's health status. It was rare for participants to communicate the feeling of achieving such success in their efforts to manage alopecia. More commonly, participants shared stories of unwanted recognition. Patient 19 recounted an example of this when she yet left their house thinking she blended in but was recognized as a cancer patient.

**‘I was at the farmer’s market and I thought I looked pretty good. And everybody was being so solicitous and saying, ‘You take care of yourself.’** I saw a friend who had a booth at the market a week later. She said, ‘[name] you looked like shit on Saturday.’ I said, ‘I wondered about that because everybody was being so nice’ [laughs]...**next time I won’t come”** (Patient 19\_2, p. 14).

Patients reported rarely leaving their homes during chemotherapy. This was largely because of physical side effects such as pain, neuropathy, or fatigue, yet some patients also said it was because wearing head coverings and managing other aesthetic-related tasks like choosing an outfit or applying makeup were too mentally and/or physically exhausting. Patient 15 explains:

**“There were times I was invited to the beach and I wouldn’t go. Not because I was too tired or didn’t feel well but because I didn’t want the hassle of fooling with my wig, but the thought of going without it was too much”**

(Patient 15\_3).

Participants like Patient 15 said their wigs tended to ward off strangers, making them less approachable for those who want to speak about cancer and hair loss. Patient 19 illustrated this in the following excerpt.

**“I don’t know why, but men get more pity [laughs]. Women are looked at...from a different point of view. I walk into a restaurant and the hostess will say, ‘oh what kind of cancer do you have?’ You talk about it and she launches into her story. People come up to me at the grocery store and start chatting. I don’t know whether it’s me or my bald head. It’s amazing how people look at you and say, ‘oh I can tell her all my troubles and it will just fall by the wayside”** (Patient 19\_1, p. 5).

Increased approachability is one of the most notably gendered aspects of chemotherapy-induced alopecia. Instances of unwanted advice were frequent and widespread across interview transcriptions. An excerpt from Patient 5 serves as an example.

‘I will wear my wig sometimes. I get funny comments from people about the wig.

**‘You shouldn’t wear that. You’re very beautiful without the wig.’** People

don’t know what to say so they talk before they think” (Patient 5\_2, p. 9).

Assuming women with cancer need or want advice speaks to Patient 19’s argument that women are perceived as more approachable than men. And as a result, women like Patient 5 endure inappropriate conversations.

The issue of distancing oneself from the public eye is complicated in the digital era. Being approached in-person is often perceived as different than online interaction. Patient 11, who is a self-described “private person,” wears wigs to blend in and deter unwanted conversations like the one Patient 5 shared. The issue of digital distancing and physical distancing has not been examined in previous literature on CIA and patient experience, yet it is an important distinction that adds to the field’s understanding of coping with alopecia. Patient 11 describes the difference:

**‘It’s normal for guys to be bald and it’s not normal for women to be bald...I**

**have a good bald head. I actually posted it on Facebook. I got a picture with**

**my brothers because they’re already bald.** At this point in time, I thought is

was kind of funny...**I felt it’s appropriate to publically post [the picture],** and I

have 300-something Facebook friends, and they’re not all close. **But I don’t**

**want to go out in public with strange strangers next door or whatever”**

(Patient 11\_1, p. 5).

Digital distance is greater than the in-person distance between neighbors and others with whom she might interact in public. Patient 11 perceived a gendered division between men and women as well as a spatial division between digital and in-person

interaction. The digital public sphere is part of today's social systems of interaction, but does not require synchronous communication between the patient and acquaintances. The choice to post a photo featuring her brothers who are naturally bald suggests solidarity, which was something Patient 11 did not communicate as part of her CIA experience except when sharing this story.

Solidarity across the gendered experience of hair loss was not reserved for relationships among family members and loved ones. As a sign of the times during which this data were collected, multiple participants referenced then presidential candidate, now President Donald Trump's hair.

"I think women are more concerned with their hair than men, but I know men who [are too]...**just look at Donald Trump. Just see what he's doing to try and keep his hair...he's like my mentor. If he can go out looking like that, I can wear scarves**" (Patient 15\_1, p. 8).

The comparison of hairstyles and appearing in public was done to lessen the severity of the situation. Over the course of chemotherapy, Patient 15 described her experience of alopecia as "progressively sadder." Even so, the reference to Trump demonstrates how much public attention a different hairstyle can garner, especially one that does not mirror gendered expectations.

**Summary.** Being a women and having alopecia were the top reasons patients were recognized as cancer patients. Patients had difficulty blending into society because of their alopecia and their gender, and they explained this difficulty by comparing their experience to that of a man's. Some had personal examples when they were in public with their bald husbands and the husbands were not assumed to have cancer.

One of the most challenging issues patients faced in public situations was an increase in approachability. Patients who valued social interaction as part of their QoL were often uncomfortable with the sudden breach in privacy after hair loss. Gendered visibility extended beyond becoming visible to other women and men. Being recognized by children in public was a memorable experience for some and demonstrated the emotional burden of being bald in public.

Head coverings were often perceived as an issue for women by women. Participants were cognizant of this, often wearing head coverings to appease other women. This finding led to a more complete understanding of why some women wore head coverings though they found them uncomfortable. Data established a communicative pattern of comparable aesthetics, where patients compared their appearance to other women with alopecia. Data provided evidence that women did not differentiate their expectations for how other women should look when visiting the clinic from other public interactions. Though this was a cancer center and a space of patient care, it was still part of the larger public sphere within which individuals construct and reinforce gendered aesthetics and social norms.

### **Chapter Conclusion**

The codes used to analyze the data organized findings and led to the development of four themes: 1) chemotherapy-induced alopecia; 2) the “mirror moment”; 3) performing social roles; and 4) gendered visibility. These themes demonstrated how the experience of an individual connects to others in a shared network of patient experience. How patients communicate about their experience of alopecia and strategies to manage it over time exist in tension with how they communicate about quality-of-life. For

example, patients shared similar “mirror moments” that revealed tension in seeing a reflection that did not match their perception of self. Such tension can be a source of distress and lower quality-of-life. An of CIA impacting QoL was the shared experience of being approached by strangers because their gendered aesthetic signaled “cancer patient.” Participants’ emotional accounts of heightened visibility inspired the theme, gendered visibility, revealing the everyday struggles of social interaction during chemotherapy-induced alopecia.

Ovarian and uterine cancer patients may feel more supported and able to discuss CIA when healthcare practitioners put it in conversation with quality-of-life. The inverse is also applicable. Efforts to evaluate patients’ quality-of-life should incorporate hair loss into clinical conversations because it is a topic that often leads patients to disclose other issues of concern. Doing this can better gauge the degree to which a patient’s concern for the public’s perception and perception of self will impact her quality-of-life during and shortly after cancer treatment. This is discussed further in the concluding chapter.

## CHAPTER FIVE:

### CONCLUSION

#### **Introduction**

This dissertation's findings confirm that chemotherapy-induced alopecia was a quality-of-life issue patients experienced differently over time. Findings were based on an analysis of communication patterns across a data set of 55 interview transcripts (1,750 minutes of audio) that resulted from interviewing 23 ovarian and uterine cancer patients at least twice each over the course of their chemotherapy. Upon completing a review of existing literature and developing the research questions, longitudinal interviewing that incorporated Ellis and Patti's (2014) compassionate interviewing technique was determined to be the optimal approach to collecting data for an interpretative analysis.

Compassionate interviewing (Ellis & Patti, 2014) encouraged more open communication, and was a more natural fit with the clinical context because patients were accustomed to telling and retelling personal stories in medical settings (Roscoe et al., 2016). Discussing her participation in the study, Patient 14 said, "I will continue to share my story. I will tell my whole health history for someone else to feel better and learn something" (Patient 14\_1, p. 4). Her willingness to share demonstrated how interviewing

should be understood as an opportunity to embrace co-construction and abstain from using a strict question-and-answer script.

Efforts to improve patient-centered care can benefit from learning how patients actually experience quality-of-life and chemotherapy-induced alopecia. Because patient-centered research is meaning-centered research, an emphasis on communication is critical. Understanding communication as central to an examination of perception, this study posed the following research questions:

**RQ1:** How do ovarian and uterine cancer patients communicate about their experience of alopecia over the course of chemotherapy?

**RQ2:** How does chemotherapy-induced alopecia influence patients' understandings of quality-of-life?

While the two research questions that guided this research were useful in developing interview questions, the findings reveal a single research question is a more useful framework for examining CIA and QoL over time. The revised research question that will be used in future research is: How do ovarian and uterine cancer patients communicate about their experience of alopecia and its impact on quality-of-life over the course of chemotherapy? An effective examination of patients' perceptions of CIA requires the researcher to incorporate quality-of-life, thus it is more effective to combine the two research questions into one.

A review of the literature indicated there was a lack of research examining chemotherapy-induced alopecia from a communication perspective and there were few studies on CIA generated in the U.S. compared to other nations, particularly those in the West. Clinicians and other healthcare professionals in the health sciences produced the



vast majority of research on chemotherapy-induced alopecia, specifically dermatology (Chon et al., 2012; Yeager & Olsen, 2011) and oncology (Frith et al., 2007; Gunnars et al., 2001; Hesketh et al., 2004), including nursing in oncology (Borsellino & Young, 2010; Can et al., 2012; Cline, 1984; Freedman, 1994; Lemieux et al., 2008; Wagner & Gorely, 1979; Williams et al., 1999) and psychology in oncology (Choi et al., 2014; Dua et al., 2015; Koszalinski & Williams, 2012). Research efforts made by scholars outside the health sciences were best represented by Hansen's (2007) ethnography of Danish rehabilitation courses with women cancer patients and Rosman's (2004) qualitative study of stigma with lung and breast cancer patients in a Parisian cancer hospital.

Excluding Williams et al.'s (1999) narrative research in nursing, most of the heavily cited literature on chemotherapy-induced alopecia and patient experience comes from Western nations outside the U.S. (e.g., Batchelor, 2001; Freedman, 1994; Frith et al., 2007; Lemieux et al., 2008; Munstadt et al., 1997). Such an absence suggested producing qualitative data on hair loss and patient experience would benefit from a health communication studies perspective focused on the ways in which language and relationships constituted meaning making and influenced quality-of-life over the course of chemotherapy.

### **Contributions**

Quality-of-life was held to a "deathbed" standard of reflection, where only the most important elements of a life well lived were included. This way of conceptualizing QoL was useful for the sake of making sense of one's diagnosis but it was too limiting, even for patients such as those included here who were nearing the end-of-life with late-stage or recurrent disease. Reserving the highest tier of QoL to issues of extreme

importance excluded day-to-day issues, which should be accounted for when examining QoL. Daily QoL concerns contributing to daily functions or pleasures were the center of concern for most patients, yet most did not directly label these experiences as pertaining to quality-of-life because of the misconception that QoL was reserved for only top tier, “deathbed” reflections. Asserting control over when and where one’s head shave will take place was a quality-of-life issue. How to function at work while managing alopecia was a quality-of-life issue. Grocery shopping becoming a distressing experience was a quality-of-life issue. These were some of hundreds of examples of daily quality-of-life issues that embody the experience of chemotherapy-induced alopecia for ovarian and uterine cancer patients.

It was difficult for this patient population with late stage cancer to discuss quality-of-life issues in the context of the everyday instead of in the context of survival or overall reflections regarding “a life well lived.” To help explain the impact of alopecia on their everyday lives, patients used “mirror moments” and looking in the mirror as reference points in their stories. Patient 22’s description of entering and exiting her shower differently to avoid the bathroom mirror and Patient 10 covering her mirrors with towels were examples of how patients experience the everyday effects of CIA. “Mirror moment” stories about small changes in behavior signified larger shifts in quality-of-life while living with alopecia. Encouraging patients to broaden the concept of quality-of-life to include everyday hardships and pleasures could allow for more open communication that could lead to improved patient care.

During the beginning phase of chemotherapy, almost all participants interpreted their experience of hair loss in comparison with the larger goal of fighting and surviving

their cancer. Speaking about cancer in this way parallels Lerner's (2004) argument that society uses the language of war to frame the experience of having cancer and seeking treatment. For most, emphasizing the battle and downplaying the aesthetics became less important for patients nearing the end of chemotherapy or the end-of-life. Data suggested the value of aesthetics increased as health improved or significantly worsened. Most patients continued to view their alopecia as a social issue. For participants in remission whose hair was slowly returning, their health status was complicated by the public perception of being a cancer patient when they no longer felt they should be seen as such.

Theme 4, gendered visibility was generated from the data and helped fill the need for research on chemotherapy-induced alopecia and quality-of-life with a gendered focus. This project highlighted how CIA made patients recognizable as cancer patients because they were women and because they were bald. Patients were adamant about CIA being a women's issue because of socially constructed gendered standards of aesthetics in the U.S. A critical discourse analysis could be performed on this data set in the future using feminist theory to examine gendered norms and how patients' language often reinforced existing standards.

Head coverings were often perceived as an issue for women by women. Data established a communicative pattern of comparable aesthetics, where patients compared their appearance to other women with alopecia. Data provided evidence that women did not differentiate their expectations for how other women should look when visiting the clinic from other public interactions. Though this was a cancer center and a space of patient care, it was still part of the larger public sphere within which individuals construct and reinforce gendered aesthetics and social norms. Participants were cognizant of this,

often wearing head coverings to appease other women. This finding led to a more complete understanding of why some women wore head coverings.

Existing arguments framing alopecia and head coverings as an issue of camouflage (Rosman, 2004; Yeager & Olsen, 2011) failed to resonate with interview participants because it was interpreted as existing in a state of hiding. Patients were open to discussing their diagnosis and alopecia with others, but on their own time and at their own volition. The concept of camouflage was an interpretive claim that did not parallel the language participants used to communicate their experience and should not be used in future interviews with this patient population.

Hair loss was an emotionally taxing shift in identity, especially for those who connected hair loss to a no longer appearing womanly, which was not synonymous with a loss of femininity. “Looking like a cancer patient” and “appearing womanly” were the same issues. This was not because patients wanted to “look good to feel better” as the American Cancer Society’s LGFB Program implied. That was far less of an important issue for the majority. Patients wanted to look less like a cancer patients and appear womanly because they were aware their appearance challenged social expectations and wanted to avoid being approached by strangers in public because they were bald and had cancer. CIA was largely an issue of aesthetics for the sake of functionality.

When patients spoke about their frustrations with CIA in terms of how it added complication to everyday functioning in public, they were more likely to connect CIA with quality-of-life. Patients were more reluctant to connect CIA with QoL when CIA was discussed in more personal terms, like it was in theme 1, the “mirror moment.”

The “mirror moment” discussed how CIA represented a disconnection between perception of self and reflection of self. Patients connected the “knowing” in “knowing others see my alopecia as signaling cancer and dying” to quality-of-life on an everyday, mundane level. However, when “knowing how others perceive my alopecia” was taken out of the conversation and the focus was redirected to how managing appearance impacted quality-of-life, most patients rejected the idea of the two being connected in the context of their personal experience but “saw how other women” could view the issue in that way. In contrast, patients were inclined to connect CIA, social interaction, and quality-of-life. Social interaction was understood as an element of QoL, and CIA hindered social interaction, therefore CIA was a day-to-day QoL issue because of its hindrance on social interaction. Concern for managing alopecia was motivated more by managing appearance for the sake of social functioning than it was for vanity.

Making distinctions between the personal and social elements of CIA was important to understanding how patients experience it. From a communication perspective, it is equally important to acknowledge the interplay between the two, understanding how the social experience and the personal are often one and the same. Goffman’s (1956) argument for the presentation of self in public and private spheres provides a language to discuss differences in the private “mirror moment” theme in conjunction with public experiences of theme 3, performing social roles and theme 4, gendered visibility but as argued in theme 1, chemotherapy-induced alopecia and quality-of-life, the social and personal are linked in an “inseparable entanglement of interdependence” (Sheep et al., 2017).

## **Goffman's (1963) Theory of Stigma**

Goffman's (1963) theory of stigma helped in understanding patients' angst toward social interaction during hair loss because they experienced what Goffman called, "an infinite regress of mutual consideration" (p. 18). Patients described this "infinite regress" as taking place during routine errands when patients knew strangers were aware of their altered appearance and strangers sensed patients were conscious of their awareness. The stigma of being "a cancer patient" (Rosman, 2004) was also revealed in the performance of social roles, especially that of career women and in family relationships. Hair loss interfered with the workplace interaction, positioned patients in a constant state of consciousness for colleagues' awareness of their CIA and head coverings that signaled a stigmatized disease.

The degree to which stigma was productive beyond its usefulness as a conceptual frame was more complicated than expected. Patients agreed with the premise of CIA and stigma in the context of comparing women's experiences of CIA compared to men's. However, they almost always rejected the association of CIA and stigma in terms of their lived reality. In theory, stigma and CIA made sense because it explained why trying to avoid "looking like a cancer patient" was important. In practice, the word "stigma" did not resonate. According to participants, cancer was so prevalent that it was difficult to associate it with being ostracized. This was key because the theory of stigma does not posit stigmatization as synonymous with exclusion or being ostracized, yet patients perceived it as such.

Social disapproval and undesirability are two separate issues within the concept of stigma. Patients communicated undesirability, which was represented in different ways

across all four themes. Being a bald woman and “looking like a cancer patient” were stigmatized in terms of having an extremely undesirable condition. The idea of the social majority disapproving of “looking like a cancer patient” does not parallel the experiences of participants. It was useful to refer to Goffman’s (1963) theory of stigma as a conceptual frame from which to gain a better understanding of the social aspects of experiencing illness, but it was less useful during actual interviews.

Based on the data analysis, it was determined ovarian and uterine cancer patients experienced substantial daily distress related to chemotherapy-induced alopecia. Because these patients were experiencing late-stage cancer with some nearing end-of-life care, patients were reluctant to mention the side effect of alopecia when asked about their overall quality-of-life. Patients’ distress concerning CIA was strongly related to the ability to function in social interaction without feeling approachable or being approached by “strangers” because of their alopecia.

The ability to perform social roles deemed important to patients’ quality-of-life such as the familial roles of partner and mother/grandmother were negatively impacted by hair loss. Most did not feel as badly about being bald as they did about their baldness signaling their diagnosis to others in their family and in the workplace and in everyday public spaces like church or the grocery store. While the concept of stigma was useful in formulating the research questions and method of analysis, the language of stigma did not resonate with patients.

Clinicians should repeatedly ask about chemotherapy-induced alopecia over the course of chemotherapy, both because it could help patients cope with the side effect and because it may generate dialogue related to other important concerns end-stage patients

may feel are too trivial to mention in clinical discussions since their disease is so serious and life-threatening. Although men and women experience many of the same cancer diagnoses, working with gynecologic cancer patients revealed some ways in which women experience ovarian and uterine cancer and chemotherapy in ways different from men. Women's social and familial roles may be impacted by cancer and chemotherapy in unique ways that deserve additional study.

### **Strengths and Limitations**

All studies have limitations and the present study is not an exception. Prompted by Munstedt et al.'s (1997) argument to examine CIA using a longitudinal approach, data collection was designed to include two to three interviews per patient during the beginning and toward the end of chemotherapy, resulting in a rather succinct data set. However, Munstedt et al. (1997) used longitudinal surveys, and did not interview patients. The reality of conducting in-depth interviews with seriously ill patients was more complicated than the plan suggested, especially when the patients are asked to participate in multiple interviews stretched over months. Patients were willing and sometimes eager to adjust their schedules to speak with me, but their health sometimes prevented this. Also, participants' appointment schedules were often beyond their control. Forming relationships with these patients, I observed how flexible they were forced to become as their lives revolved around managing chemotherapy. From their perspective, participating in interviews about CIA was one part of a larger process. For patients to continue spending hours in conversation revealing personal information, it was critical to emulate flexibility as an interviewer that was similar to what they demonstrated as patients.



The findings are limited by a small sample size of 23 participants and a relatively small data set of 55 interviews with 1,750 minutes of audio for analysis. Those who perform discourse analysis, for example, could interpret this data set as too large, limiting the opportunity for close readings. The data set used for this analysis was adequate to allow for a rigorous and thorough thematic analysis, however the patient population under analysis was limited in its diversity from a demographic perspective, especially in the areas of race/ethnicity, sexuality, and access to health insurance. The study was limited to ovarian and uterine cancer patients, which was considered a strength because of its specificity but could be interpreted as a weakness because it involved only two types of cancers and was specific to women.

### **Future Directions**

The project resulted in a wealth of data. As a working document, this dissertation will be segmented into useful parts and published as journal articles in the fields of health communication, gynecologic oncology, quality-of-life studies, and qualitative method. I am currently working on an arts-based project inspired by data collection and intend to involve online spaces as well as the local community in ways this dissertation did not.

I envision this project moving in the direction of participatory action research while continuing to further Ellis and Patti's (2014) argument for compassionate interviewing. This research could encourage more collaboration among disciplines as well as between healthcare institutions the communities they serve. I intend to continue building this research and exposing audiences to CIA as a women's health issue and QoL issue.

Two years ago, I attended a grant-writing workshop where a professor said “think of all the things that could be done with your research if you had more resources. Who would you include? What ways could you expand the project’s reach? I’m sure you have running lists. A grant can help you achieve some of these goals, so keep adding to your list and apply for funding.” This dissertation project was not funded, and the lack of funding limited what could be done. Like the professor hosting the workshop, I have a list of aims that could be better met with funding. I intend to secure grants to support studies inspired by this one that will have more layers of analysis and a greater reach. Holding a series of focus groups with gynecologic cancer patients who could help develop an improved interview guide could improve the interview content and format. Also, I intend to recruit a research team including gynecologic cancer patients who would be willing to serve as community stakeholders and co-interpreters who could help generate strategies for how to integrate the gynecologic cancer community and assess their needs and concerns, especially those related to chemotherapy-induced alopecia and quality-of-life.

### **Recommendations for Clinicians**

In an era of individualized care, quality-of-life and side effect management is a growing interest in oncology and women’s health. Those who care for patients on a daily basis would benefit from exposure to this project and research like it as well as recommendations for what to do with the information. What are some practical, micro-interventions that can be easily incorporated into everyday clinical communication?

Physicians, social workers, and nurses, among others, are encouraged to incorporate dialogue that is focused on chemotherapy-induced alopecia into the patient-

provider exchange over time. A few focused questions that are addressed throughout the course of chemotherapy may help determine how much of an issue CIA is and provide insight into patients' coping processes. Knowing the topic of hair loss was perceived as more of a social deterrent than other side effects and less dire than other side effects such as fatigue or neuropathy, healthcare practitioners can use the topic of CIA as a way into discussions of larger scale issues such as quality-of-life. Questions along the lines of the following are recommended: 1) "How does your hair loss impact you?" or 2) "How are you handling hair loss?" The next step involves putting QoL and CIA in conversation with one another using questions such as the following: 3) "How does your hair loss impact your quality-of-life?" 4) "What would it take for you to have a higher quality-of-life during chemotherapy?" or 5) "What would it take for you to feel more comfortable with your hair loss?"

Question 5 could be used as a conversational opening to make referrals if patients communicated interest in seeking direction/information. Using this project's site of research of example, some patients who were interested in wigs were unsure where to start, saying they spent too much money and time online searching for wigs. Those who did this said it was isolating and confusing. The spaces and people to which patients can be referred are limited, but there are more options than most participants were aware, which furthers the argument for needing to incorporate the above questions into the clinic. For example, this project's site of research had a non-profit lodging facility that was largely unknown to have free wigs and employees who helped patients sort through options and make decisions. Only one interview participant was aware of the lodge's free wig program, yet it was located approximately 300 yards from the gynecologic

clinic. This was a missed opportunity to increase access to wigs, and will be part of future research critically examining cranial prostheses as a symbol of access to resources that can help patients who want to manage their appearance by wearing wigs.

Data confirmed a referral to the American Cancer Society's "Look good, feel better" Program does not resonate with patients who are concerned about CIA in a way that does not involve femininity, which is all LGFB represents. Patient 16, for example, wanted to "look like my natural self" but was adamant against incorporating cosmetics into her cancer experience, which is the overall intention of the LGFB Program. A second example was Patient 7 who was "a hippie" with a ponytail and wanted a wig with a ponytail. She was interested in the "Look good, feel better" motto but against the values of the program. Referring patients like these to the LGFB program may dissuade them from wearing wigs. Putting alopecia in conjunction with quality-of-life helps ground the conversation in issues of social interaction, meaning making, and everyday function and may improve the patient experience in and outside the clinic.

## **Chapter Conclusion**

Working with this patient population reinforced health and relationships as key tenets of a high quality-of-life. Patient 13, who had recurring ovarian cancer, explained how seriously ill patients lived in a state of oscillating from poor health to manageable health, then back to poor. Health remained important, but it took on a less hopeful meaning<sup>3</sup> that was rooted in uncertainty. Meanwhile, relationships came to the forefront of importance, positioning communication and interaction as central components of

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<sup>3</sup>Refer to Basu (2010) for an analysis of women's health and hopelessness when access to healthcare is an impossibility

quality living. As a result, chemotherapy-induced alopecia became embedded in the larger schema of quality-of-life because hair loss impacted patients' relationships and often served as a barrier between patients and social interaction. As discussed in the theme 3, performing social roles, mothering children and young adults became a source of emotional struggle for patients whose children/grandchildren withdrew after hair loss/head shaves. CIA shifted the relationship, as patients perceived their children struggling with their alopecia because it signified the severity of their disease.

Research on chemotherapy-induced alopecia and quality-of-life must continue to emphasize communication because patient-centered care is meaning-centered care. This research functions with an epistemological understanding that there was no single starting point by which to measure patient experience nor was it possible to have a complete understanding. Patients' experiences of CIA were already being crafted, told, and retold before interviewing took place and continued after they were completed (Bochner, 2014; Charon, 2004; Frank, 2013; Roscoe et al., 2016).

For many, hair loss was "a top concern" during chemotherapy ranging from top five to top ten of concerns, but it was not concerning in comparison to substantial losses, like the loss of normalcy that accompanied a cancer diagnosis, or the loss of independence, or loss of life. Some referred to CIA as trivial in comparison to life-or-death and then said they were unsure why they made such a drastic comparison. American society's standards construct the expectation for cancer patients to fight for survival and downplay experiences that are not life-or-death (Mukherjee, 2010; Lerner, 2004). If this was the standard from which to measure everyday life, than we run the risk of snowballing the lived experience into a frame of thinking where "nothing really

matters.” Such thinking does not do justice to the lived reality of being a bald woman with cancer who has to function in public while knowing everyone else knows she has cancer.

Ovarian and uterine cancer patients may feel more supported and able to discuss chemotherapy-induced alopecia when it is put in conversation with quality-of-life. Efforts to evaluate patients’ quality-of-life should incorporate chemotherapy-induced alopecia because it is a topic that often leads patients to disclose other issues of concern, especially issues with other side effects as well as outside-the-clinic concerns that impact their ability to endure chemotherapy. Communicating chemotherapy-induced alopecia as a daily quality-of-life issue can better gauge the degree to which a patient’s concern for public perception, social interaction, and perception of self will impact her quality-of-life during and possibly after chemotherapy.

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APPENDIX A:  
INTERVIEW GUIDE

MCC 18102: Expanding Conceptions of Patient-Centered Dialogue  
Date initially submitted: 11/26/14  
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IRB study 19393

How are women cancer patients expected to look?

What is your defining of coping?

In what ways has the loss of your hair impacted you?

What are some strategies you use to help you cope with the loss of your hair?

On a scale of 1-5, how would you rate the quality of life, where  
1= very poor 2= poor 3= average 4= good 5=very good

In what ways does a patient's appearance matter? Are there times when it does not?

What are the appearance-related expectations for women experiencing illness?

In what ways are expectations related to appearance different for women who are considered healthy?

Do you feel you are expected to look a certain way?

Does the way a woman looks relate to the way she might feel? Does this change after receiving a diagnosis?

Do you consider visiting this salon part of the overall Moffitt experience?

APPENDIX B:

PATIENT DEFINITIONS FOR QOL

Sequence ID	Participants' responses to the prompt: "To me, quality-of-life means..."
1	"Going out to eat with family; being my own person; not to be waited on by anyone; walking by myself; being me"
2	"Feeling good about my Self, health, and spiritual faith. Centered and in good relationship with myself" & "Support, loving care, desire and trust God to help through each trial"
3	Written in Spanish: "Calidad de vida es tener presente a Dios y aceptar su voluntad" Translated in English: "Quality of life is to have God present and accept his will"
4	"Quality of life means Health body and image, so if you look great you will feel better with that being said it will be easier to cope with depression and anxiety"
5	"Able to care for my family and myself. Become more faith-full towards God. Stay soft in spirit and be more to 'play' with my kids"
6	"Faith, Family, Friends"
7	"Love, kindness, consideration, family, mobility, nature, God"
8	"Looking forward to the day; always looking forward to something and caring for God"
9	"Having family and friends that you enjoy being with and interests that keep you involved and alert"
10	"Staying healthy enough to work and support myself. It was hard for me to be financially dependent on others. But also making the time to enjoy life. Spending time with family and friends. If I learned anything from this experience it is that life is precious and you never know how much time you have on this earth."

11	"Being able to enjoy life and having energy: time to do lots of 'fun' things-travel, music, etc. Being able to feel 'normal'-not to have people feel sorry for you-ever."
12	"Being there for my family as long as possible and doing things that pass the time"
13	N/A
14	"Independence, lack of pain, interest in doing things and socializing, being able to lead a 'normal' life"
15	N/A
16	"To be who I am, that is the most important thing to me"
17	"Being able to walk around, get out, not reliant on people taking care of you; when you are not in treatment all the time"
18	"Quality of life for me is getting the most of each day that my mind and body can sustain"
19	"Living a life that is supported by loved ones and friends; to achieve desires and to respond; interact and share with like-minded individuals; Love is the basis of all thought, words, and action"
20	"When I am not in pain; able to do for myself and not depend on someone else; able to cook and take a bath"
21	"Being able to function and live life as close to what life was prior to diagnosis, maybe with some restrictions but not to the point of those restrictions are prohibiting you from living, loving, laughing"
22	"Independence and doing what I want when I want"
23	"The ability to experience all the pleasures of life in the moment-mindfulness"

APPENDIX C:

DEMOGRAPHIC CATEGORY 1

Sequence ID	Diagnosis	Age	Marital Status	Children
1	Ovarian_metastatic	73	Y	Y
2	Ovarian_IIIc	67	Y Unioned	Y
3	Ovarian_IIIc_ high grade serous	46	Y	Y
4	Uterine_Ia_grade 3	39	Y	Y
5	Ovarian_III_ late stage	49	Y	Y
6	Uterine_Ic_ high grade serous	65	Y	Y
7	Uterine_IIIa_ Grade 3	59	Y	N/A
8	Ovarian_IIIc_ high grade serous	81	N Widowed	Y
9	Uterine_IIIc recurrence	73	Y	Y
10	Ovarian_IIIc_ high grade serous	44	N Single	N
11	Ovarian_IIIc recurrence	54	Y	N
12	Uterine_IIIc	62	N Divorced	Y
13	Ovarian_IIIc recurrence	58	N Single	N/A
14	Uterine_Ila recurrence	77	Y	Y

15	Ovarian_IIIb high grade	61	Y Partnered	Y
16	Ovarian_IIIc	83	N Widowed	Y
17	Ovarian_low Grade serous	41	Y	N
18	Ovarian_IIIb_ high grade serous	66	N Widowed	Y
19	Ovarian_IIIb recurrence	70	Y	Y
20	Ovarian_IV serous recurrence	76	N Single	Y
21	Ovarian_IIIc recurrence	49	Y	Y
22	Ovarian_high grade	78	N Widowed	N/A
23	Ovarian_IV	63	N Divorced	N/A

*\*(avg. = 62 years; range 39-83 years) (14 Married/Partnered) (16 have children)*



APPENDIX D:

DEMOGRAPHIC CATEGORY 2

Sequence ID	Sexuality	Race	Hispanic	Education	Insurance	Physician
1	S	W	Y	< High school	Y Private Medicare	Shahzad
2	G	W	Y	Some college	Y Private Medicare	Shahzad
3	S	W	Y	College	N Uninsured	Shahzad
4	S	Other	Y	College	Y Private	Wenham
5	S	W	N	Technical school	Y Spouse Workplace	Shahzad
6	S	W	N	Postgraduate	Y Private Medicare	Shahzad
7	S	W	N	N/A	N/A	Wenham
8	S	W	N	Postgraduate	N/A	Wenham

9	S	W	N	College	Y Private Medicare	Shahzad
10	S	W	N	College	Y Private	Wenham
11	S	W	N	College	Y Private	Apte
12	S	W	N	< High school	Y Medicare Medicade	Apte
13	N/A	W	N	Postgraduate	N/A	Apte
14	S	W	N	College	Y Private Medicare	Wenham
15	S	W	N	High school	Y Workplace	Wenham
16	S	W	N/A	N/A	N/A	Wenham
17	S	W	N/A	N/A	N/A	Shahzad
18	S	W	N	College	Y Private Medicare	Shahzad
19	S	W	N	Postgraduate	Y Private	Shahzad
20	S	AfAm	N	N/A	N/A	Shahzad
21	S	W	N/A	N/A	N/A	Chon
22	S	W	N/A	N/A	N/A	Shahzad
23	S	W	N/A	N/A	N Uninsured	Shahzad

APPENDIX E:

IRB AND SRC APPROVAL LETTERS



RESEARCH INTEGRITY AND COMPLIANCE  
Institutional Review Boards, FWA No. 00001669  
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799  
(813) 974-5638 • FAX (813) 974-7091

7/14/2015

Meredith Clements  
USF Department of Communication  
4202 E Fowler Ave CIS 3057  
Tampa, FL 33620

**RE: Expedited Approval for Initial Review**

**IRB#: Pro00019393**

**Title: Expanding Conceptions of Patient-Centered Dialogue: Female Cancer Patients and the Aesthetics of Disease**

**Study Approval Period: 7/14/2015 to 7/14/2016**

Dear Ms. Clements:

On 7/14/2015, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents contained within, including those outlined below.

**Approved Item(s):**

**Protocol Document(s):**

[2015.03.17 Letter of Support from Salon Supervisor](#)

[2015.06.01 Protocol](#)

[Dr. Thomas Brandon HOB Program Leader Approval Letter](#)

**Consent/Assent Document(s)\*:**

[07.05.15 Consent Form.pdf](#)

\*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab. Please note, these consent/assent document(s) are only valid during the approval period indicated at the top of the form(s).

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR 56.110. The research proposed in this study is categorized under the following expedited review category:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval via an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) calendar days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

A handwritten signature in cursive script that reads "John A. Schinka, Ph.D.".

John Schinka, Ph.D., Chairperson  
USF Institutional Review Board

November 23, 2015



Meredith L. Clements, MA  
University of South Florida  
Department of Communication  
4202 E. Fowler Avenue, CIS 3057  
Tampa, Florida 33620

**RE: MCC 18102: "Expanding Conceptions of Patient-Centered Dialogue "**

Dear Ms. Clements,

The Behavioral Sub-Committee of the Moffitt Cancer Center's Scientific Review Committee (SRC) has reviewed your **response to approvable determination dated 11/20/2015** for your research protocol. The revised **protocol dated 11/20/2015** is approved as written for use at the Moffitt Cancer Center pending approval of the Institutional Review Board (IRB).

It is your responsibility to ensure that all Moffitt staff (Nursing, Pharmacy, Data Management, etc.) are informed and aware of the details of the project. The Scientific Review Committee encourages the use of in-services for those projects which are complex or require special attention.

All changes made to protocols approved by the SRC must be submitted to the Protocol Review and Monitoring System office. Changes made to the protocol document require SRC review and approval. Minor changes (i.e. changes to personnel, non-scientific changes, changes that do not affect patient participation) will be expedited through the SRC review process.

If this project is not being managed by the Clinical Trials Office or Clinical Research Unit, then it is your responsibility to follow through with all requirements for submission to the IRB. All IRB approvals are required to be documented in Oncore, and all associated regulatory documentation (signed applications, IRB approval letters and IRB approved consent forms, etc.) are to be saved in the appropriate study folder in the e-binders directory at J:\ebinders.

Oncore is the Cancer Center's mechanism for submission and review of materials requiring Scientific Review (SRC) and Protocol Monitoring (PMC). If you need access to Oncore, please contact Jeryl Madden, Oncore Administrator, at 745-6964 for assistance.

Sincerely,

A handwritten signature in black ink, appearing to read "Susan Vadaparampil". The signature is fluid and cursive, with a long horizontal stroke extending to the left.

Susan Vadaparampil, PhD.  
Vice-Chair, Behavioral Sub-Committee  
Scientific Review Committee

cc: Lori Roscoe, PhD, Co-Principal Investigator

## APPENDIX F:

### PUBLICATION STATEMENT

Both *Annals of Internal Medicine* and *JAMA Oncology* gave me permission via the telephone to feature the poems I previously published in their journals. *JAMA Oncology* said they did not need to provide me with written permission to reprint because the poem would be featured in a dissertation. *Annals of Internal Medicine* said they do not provide written permission because I am the author and have the right feature my work in other venues pending their journal is cited, which it is.