Title
Sexuality and Femininity in Older Women After the Diagnosis of Early Stage Breast Cancer

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Publication Date
2020

Peer reviewed|Thesis/dissertation

UNIVERSITY OF CALIFORNIA

Los Angeles

Sexuality and Femininity in Older Women After the Diagnosis of Early Stage Breast Cancer

A dissertation submitted in partial satisfaction of

the requirements for the degree

Doctor of Philosophy in Nursing

by

Melissa Diane Scalia

2020

ABSTRACT OF THE DISSERTATION

Sexuality and Femininity in Older Women After the

Diagnosis of Early Stage Breast Cancer

by

Melissa Diane Scalia

Doctor of Philosophy in Nursing

University of California, Los Angeles, 2020

Professor Huibrie C. Pieters, Committee Chair

Experiences and perceptions about sexuality of older breast cancer survivors are unspoken, overlooked, neglected and underexplored in clinical settings and the scientific literature. Stereotypes about age and sexuality impede sexual assessment and conversations with these women. Consequently, little is known regarding sexuality and femininity subsequent to the diagnosis of breast cancer from the distinctive knowledge base, worldview and voices of older women. The purpose of this qualitative dissertation was to understand and describe perceptions of sexuality and femininity among women with early stage breast cancer who were 65 years and older at the time of the interview. The rationale for this study was influenced by the assumption that the sexuality of older women is impacted by the diagnosis and treatment of early breast cancer. The purposive sample of 19 participants, all residing in Southern California, participated in personal interviews from August 2015 to January 2018. Qualitative description with a constructivist grounded theory framework for data collection and analysis was used to organize the data into three overarching themes: receiving the diagnosis, experiencing

sexuality and describing femininity. Each of these themes was subsequently organized into three subthemes of inner processes, outer processes and moving forward. The findings vividly illuminated this sample of older women's perspectives on the significance of sexuality and femininity in their lives subsequent to the cancer diagnosis. The preservation of femininity was challenged by the diagnosis and treatment of breast cancer. Additionally, maintaining or re-initiating physical intimacy after treatment required strategizing for engaging in intimate encounters. Knowledge generated by this study reveals the opportunity for health care providers to understand and address the sexuality and femininity needs of older women after the diagnosis of early stage breast cancer. Recommendations for future studies with older breast cancer survivors include the identification of barriers to discussing sexuality among patients and oncology clinicians, development of guidelines for effective communication and improvement of the assessment of sexuality and femininity.

The dissertation of Melissa Diane Scalia is approved.

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2020

Dedication

This work is dedicated to all the women who shared their life experiences regarding breast cancer, aging, sexuality and femininity. Their altruistic contribution has forever enhanced our understanding of the journey of older women subsequent to the diagnosis of breast cancer.

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Acknowledgments

My sincerest appreciation for the financial support I received for this doctoral dissertation from the Greater Los Angeles Oncology Nursing Society, the Jumpei Wantanabe Memorial Endowment, the Deloras Jones Nursing Scholarship and the University of California at Los Angeles School of Nursing.

Thank you to the many individuals who made this journey possible. I would like to express my gratitude to my committee members: Drs. Janet Mentes, Carol Pavlish and Annette Stanton for encouraging and guiding my academic scholarship. My sincere appreciation goes to Dr. Sally Maliski for supporting me as I began this journey.

I would like to express my deepest gratitude to Dr. Huibrie Pieters, my committee chair, for her devotion to this project. Her commitment to intellectual rigor continuously inspires and shapes me. Many thanks to her for guiding me through this truly humbling experience and for the immeasurable hours we spent together honing my critical thinking to achieve more than I could have ever expected.

Finally, I thank my beloved family for their encouragement and support throughout my doctoral journey and for always believing in me.

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Chapter 1: Introduction

The purpose of this qualitative descriptive study (Sandelowski, 2000; Sandelowski, 2010) was to understand and describe the multidimensionality of older women's perceptions of their sexuality and femininity subsequent to treatment for early stage breast cancer. The diagnosis of breast cancer and treatments commonly alter sexuality, sexual function and quality of life (Gandhi et al., 2019; Wang et al., 2013). Furthermore, the loss of a breast for some women is not merely the removal of a diseased body part, but was found to be regarded as a disfigurement that caused a discrepancy between the self-assessment and societal perception of womanhood and femininity (Sun et al., 2018). Investigation of the significance of sexuality and femininity in the lives of older breast cancer survivors is essential to guide clinical practice because communication regarding sexuality and femininity concerns in the clinical setting is scarce as both older women (Yee, 2010) and their health care providers (Fitch, 2018) wait for the other party to initiate conversations. Hence, an exploratory investigation into the impact of breast cancer on sexuality and femininity among older women is critical to navigate clinical discussions.

Background and Context

While sexuality is an integral aspect of well-being for breast cancer survivors (Ghizzani et al., 2018), the disease and its treatments have been found to negatively and profoundly impact sexual well-being and intimacy, which can persist for many years (Ussher et al., 2012). Yet, despite this existing knowledge, conversations about potentially negative impacts were not occurring with cancer survivors and their partners in oncology clinical settings (Fitch, 2018; Jung & Kim, 2016). Oncology nurses waited for survivors to introduce the topic of sexuality (Fitch, 2018), but older women were hesitant to initiate the topic (Yee, 2010), and breast cancer survivors expected health care professionals to broach the subject (Den Ouden et al., 2019). While some researchers

suggested that the onus rests on health care providers to initiate discussions of sexual issues (Yee, 2010), others more recently noted that it is insufficient to rely solely on clinicians to initiate the subject (Canzona et al., 2019).

Further compounding the difficulty of sexual assessment and conversations with older breast cancer survivors is the sexual stereotypes about older women. In a recent systematic review of qualitative research, negative stereotypes were found to exist in the evaluation of older adults' sex lives (Sinkovic & Towler, 2019). Perceived as asexual, older adults, including women, have been excluded from sexual health research (McHugh & Interligi, 2015, p. 89). Perceptions of asexuality may also be internalized by older women themselves and impact their self-perceptions as sexual beings. Public policy agendas and research were previously shaped by these pervasive stereotypes (Hinchliff et al., 2018). Prevalent myths persist in North American and other western societies that impede older women's sexual life regarding masturbation, same sex partner intimacy, sex therapy, and the implication that menopause signals loss of libido and an end to sexual intimacy (Messelis et al., 2019, pp. 296-298). Overall, while the state of science of older women's sexuality is advancing, societal beliefs continue to negate sex in old age (Diniz et al., 2019).

For many women the female breast is personally and culturally meaningful as the ultimate symbol of femininity (Schlebusch & Van Oers, 2019). Consequently, loss or change of breast tissue integrity due to breast cancer treatments can potentially pose a threat to femininity self-evaluation (Boquiren et al., 2016). Breast cancer is a disease of aging with 61 years the median age for a first-time diagnosis in the United States (DeSantis et al., 2016). However, knowledge is limited regarding older breast cancer survivors' experiences, perceptions and needs related to femininity after breast cancer. The experiences of losing breast tissue, surgical reconstruction and perceptions of their femininity among older breast cancer survivors remain unknown. Additionally lacking is

an age-specific assessment tailored to the distinctive sexual needs of older breast cancer survivors in clinical settings.

Current Gaps in Practice and Science

Sexuality is a vital component of life for older adults (Smith et al., 2019). However, in the limited research conducted with breast cancer survivors, the primary focus continues to be the sexuality of younger women aged 50 years or less (Avis et al., 2018). Additionally, the underrepresentation of older adults in cancer clinical trials (Hurria et al., 2015) and the existence of the gold standard of overall survival as the primary endpoint in these trials minimize the importance of quality of life for older adults (Wildiers & Le Saux, 2020, pp.1066-67). Thus, investigation is warranted to explore sexuality and femininity among older women who were treated for early breast cancer to inform conversations in clinical settings. The purpose of this study was to understand and describe perceptions of sexuality and femininity among women with early stage breast cancer who were 65 years and older at the time of the interview. The following two specific aims guided the research:

1) Explore, analyze and describe the everyday experiences, perceptions and expressions of sexuality and femininity among older women subsequent to treatment for early stage breast cancer.
2) Describe the psychosocial processes that can guide clinical communication with women aged 65 years and above to navigate the experiences of sexuality and renegotiate feminine identity subsequent to a diagnosis of early stage breast cancer.

Overview of the Study Design

A qualitative approach was deemed most appropriate to research the two complex and underexplored concepts of sexuality and femininity within the context of aging. Constructivist grounded theory, an interpretive methodology, guided data

collection and analysis (Charmaz, 2014). However, because recruitment stretched over many months and the data were not saturated, data collection was stopped before theoretical saturation was acquired. Therefore, the pragmatic and less interpretive approach of qualitative description that does not require data saturation was used for the final analysis (Sandelowski, 2000; Sandelowski, 2010). The rich descriptive language derived from this qualitative study vividly illuminated older women's perspectives on the significance of sexuality and femininity in their lives subsequent to the diagnosis of early stage breast cancer.

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Chapter 2: Review of Pertinent Literature

Breast cancer is the number one diagnosis of cancer in women worldwide and the most common form of cancer diagnosed in women residing in the United States (US) (American Cancer Society, 2019). The lifetime probability of a woman developing invasive breast cancer is one in eight, with an estimated 268,600 new cases diagnosed in the US alone in 2019 (American Cancer Society, 2019). The most recent estimated population of breast cancer survivors in the US as of January 1, 2016 was more than 3.5 million women (Miller et al., 2016). With a median age of diagnosis for women in the US of 61 years old (DeSantis et al., 2016), breast cancer survivors over the age of 65 constituted a large group of the cancer survivor population (National Cancer Institute, 2014). Furthermore, the population of the US is aging and the projected population of older adults living in the US in 2050 is estimated to reach 88 million (Janssen, 2016). Current estimates of the overall cancer statistics indicate that there will be 22.1 million cancer survivors in the US by 2030, with one in six persons over 65 years of age living with a history of cancer (American Cancer Society, 2019). On a global level, the incidence of cancer by 2035 is predicted to reach 24 million with 60% or 14 million of the new cases in individuals 65 years or above, a rise from 2012 of 48% (Pilleron et al., 2019). As is the case in the US, the global population of older persons is also projected to increase. In 2050 the global population of older people is estimated to reach approximately 2.1 billion (United Nations, Department of Economic and Social Affairs Population Division, 2017). Thus, the already large number of breast cancer survivors in the US and worldwide is expected to increase.

The multiple advances that have been made in the prevention, early diagnosis and the treatment of breast cancer are associated with the decline in mortality rate of female breast cancer patients over the past decades by 40% with 20 deaths per 100,000 opposed to the peak incidence in 1989 of 33.2 deaths per 100,000 (American Cancer

Society, 2019). However, the disease continues to be the second leading cause of death due to cancer in the US with an estimated 41,760 women who are expected to die of the disease in 2019 (American Cancer Society, 2019). Disparities continued between white and black females in regards to the survival rates, with black women having a lower survival rate of 81.5% compared with 90.8% (Howlader et al., 2018). However, despite the many deaths associated with the disease, women diagnosed with early stage breast cancer can expect to live a long disease-free life since the 5-year survival rate is 85% (American Cancer Society, 2017a).

In a seminal oncology publication, the quality of life model as applied to cancer survivorship was based on the interaction between four domains of well-being: physical, spiritual, psychological and social (Ferrell et al., 1998). This interaction underlaid a sense of unity for the individual (Ferrell & Grant, 2004 as cited in Hewitt, Greenfield & Stovall, 2005, p. 68). The systemic treatments for breast cancer have potentially severe and generalized consequences on sexual function and quality of life (Schover, 2017). As these consequences also may have influenced the psychosocial domains, issues such as sexuality and femininity must be included in research to reflect the significance of these aspects in the lives of breast cancer survivors and guide clinical practice. However, the primary intent of many randomized clinical trials and standards of care had been focused on cure and overall survival indicators, which are not surrogates for enhancement of quality of life domains (Hwang & Gyawali, 2019). Thus, while overall survival is an important factor in randomized clinical trials, the limited focus on survival potentially minimizes the quality of life aspects of sexuality and femininity for older breast cancer survivors.

The phrase “cancer survivor” was introduced and popularized in the literature with a seminal work by the Institute of Medicine titled *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt et al., 2005). However, older women themselves did

not identify as breast cancer survivors (Pieters & Heilemann, 2011). Similarly, in my personal experience as an advanced practice nurse who worked in gero-oncology, the women I met in the clinical setting identified themselves in terms of social relationships such as mother, wife, grandmother or caregiver. Their inherent identity did not change and was not associated with the term cancer. However, for the purpose of this literature review, older women subsequent to their diagnosis will be referred to as breast cancer survivors. Since this population is commonly referred to as breast cancer survivors in the literature, this phrase is expected to continue to be used.

We live in a society that commonly equates a woman's body image with sexual attractiveness and femininity. The culturally developed concept of femininity and self-identity may be threatened by a breast cancer diagnosis because sexuality after the diagnosis can be altered by treatment modalities with short- and long-term side effects which influenced sexual self-assessment and expression with distressing concerns for women and their significant others. In regards to age, while it has been established that women 70 years and older who were treated for early stage breast cancer confronted distinctive barriers such as a desire to maintain control and independence, care giving concerns, along with the existence of co-morbid conditions and diseases (Pieters et al., 2011; Pieters et al., 2012), research continues to be primarily focused on sexuality and femininity in breast cancer survivors aged 50 years or less, excluding older women (Avis et al., 2018). Thus, further investigation is warranted to explore quality of life aspects, especially the understudied components of sexuality and femininity among older women who were treated for breast cancer.

Purpose

The purpose of this review is to understand the state of the science on sexuality and femininity among women 65 years and above subsequent to the diagnosis of breast

cancer. This review involved advanced systematic searches of databases that focused on the larger impact of breast cancer on aging, sexuality and femininity within the elements of the quality of life model domains of psychological, physical, spiritual and social aspects.

Database Search Strategies

For the purpose of this review, advance search strategies of the databases Medline, CINAHL, PubMed, Web of Science, PsycINFO and ProQuest included subject, citation, author searches, journal references and footnote chasing. The original search commenced utilizing four key words of the central concepts identified as “breast cancer”, “sexuality”, “femininity”, and “older women”. The subsequent searches were redefined according to each database with the use of combination of keywords, terms, Boolean operators and truncation symbols to optimize each search outcome. Scholarly investigations published from 2000-2019 were screened and evaluated for applicability to the study. Study appraisal included qualitative and quantitative methodologies and reviews of literature available in the English language. A scarce body of work, only nine studies was identified in the initial electronic search. In addition, the references of relevant articles were hand searched to identify approximately 18 publications that were missed with the electronic search.

In the subsequent review of literature, the breast cancer diagnosis was situated in aging. Then, for clarity, the review of the potential physical and psychological impacts of the diagnosis and treatment within the context of aging were separated in sexuality and femininity. Thus, although the entwinement of the physical and psychological domains cannot be teased apart, the two components are presented separately here.

Aging

This discussion starts with the normal and individualized changes that commonly accompany aging that impact the physical and psychological expressions of sexuality and femininity among women. Then common age-related stereotypes and cultural expectations that additionally influence self-perceptions with advancing age are described along with the possible challenges of a breast cancer diagnosis and treatment outcomes.

Age-related physical sexual changes

Aging, including physiological aging, is individual (Meiner, 2015, p. 17). However, various visible physical changes associated with the passage of time may be constant reminders of growing older in a world where youth is venerated. Visual acuity and adaptation decline frequently require assistive devices. Loss or changes in hearing can necessitate auditory assistive devices. Older women may note a diminished quantity not only of scalp hair but also pubic and extremity hair, and the hair may be coarser and grayer. All these elements of change related to the natural aging process put the older woman previously diagnosed with breast cancer at risk for alterations of her sexual self-image or assessment as a sexual being.

Among older breast cancer survivors, changes associated with the natural aging process, chronic illness, medications or a direct result of breast cancer treatment may leave women uncertain about their experiences (Granville & Pregler, 2018; Lovelace et al., 2019). Related to sexual expression, physiological changes associated with aging such as chronic illness and disability interfered with sexuality while endocrine, vascular and nervous system dysregulation commonly affected sexual function (Tetley et al., 2018). Losses of muscle tone and body composition changes that are part of the aging process contribute to weakened orgasm intensity. Fatigue as a result of ill health can negatively influence sexual activity in community-dwelling older women (Erens et al.,

2019). These factors possess the potential to disrupt or alter the concept of sexual self, sexuality, sexual function or responsiveness.

Older individuals, including cancer survivors, maintained sexual interest and the ability to engage in sexual activities, thoughts and erotica throughout the life span, and an intact health status sustained sexual functioning until the end of life (De Lamater, 2012). For women over the age of 50 common barriers to sexuality, sexual functioning or activity included medication side effects, availability of functional sexual partner, relationship conflicts, health of a sexual partner and lack of privacy due to the living environment (Schover, 2017). Chronic diseases that can impact the sexual response and sexuality of older women include thyroid disorders, diabetes, cardiovascular disease, hypertension, depression, anti-estrogens, oncologic agents, lipid lowering medications, anti-psychotics and opiates (McCabe et al., 2016). In addition to the natural aging process and common age-related chronic diseases, the decline of estrogen due to ablative therapies among women who were treated for breast cancer also may negatively influence the sexual response cycle and sense of sexuality (Biglia et al., 2015; Ussher et al., 2012).

For older adults, sexuality was often a shift from genital sex to intimacy, and affection was expressed through acts of touching, intimate kissing, cuddling, masturbation, sexual talk, flirting or teasing along with the enjoyment of erotic media such as movies or magazines (Skalacka & Gerymski, 2019). Engagement in the sexual activities of kissing, fondling and petting were associated with an older woman's overall sense of enjoyment of life (Smith et al., 2019). Culture, religious beliefs and family traditions may also affect sexual expression and behavior. All the dimensions of sexual satisfaction contributed to the wholeness of the older adult's overall life satisfaction (Skalacka & Gerymski, 2019). Specifically, among older women with a diagnosis of

breast cancer, the decreased frequency of engagement in sexual activity after breast cancer contributed to sexuality concerns (Soldera et al., 2018).

Older women, aging stereotypes and ageism

Taking a feminist stance in a society where older women are despised and feared and young women are valued for fertility and beauty, aging women have often been described as a target of pity and ridicule with the consequences of scientific reductionism (Gannon, 1998). As a society, we are familiar with the stereotype of the crone or witch and the way this figure has been portrayed in fairy tales, legends or myths. The crone-witch may have been positioned as a wise advisor in her community, but she was also commonly feared as dangerous and a constant suspect in any evil which befell the community. Other grotesque stereotypes in western society are also often portrayed as older women. These images may include the medusa, a bearded or mustached woman, fat lady, tattooed woman or starving woman. We associate many of these women in western culture with freak shows, circuses, horror movies or comedic television shows (Ylanne, 2015, pp. 374-375).

Older women who viewed signs of physical aging as unattractive had a poor body image and experienced decreased sexual desire that became a source of depression and anxiety (Estill et al., 2018). Conversely, the same study found that mid-life and older women who viewed aging as a positive process perceived sexual desirable self and experienced enhanced sexual desire, quality of sexual experiences and interest in sex.

Utilizing a qualitative research approach, researchers in France explored the experiences and practicalities of aging women to conceal or repair body changes in pursuing “the paradox of impossible beauty” (Macia et al., 2015, p. 174). In the sample of women aged 65-75 years old, participants concluded aging was impossible to effectively hide, and that the “ravages of time are inevitable” (p. 182). The choice

between plastic surgery and “letting oneself go” (p. 175) was socially unacceptable and stigmatized. Overall, the women accepted a loss of beauty that occurred with advancing age as in the summation of one participant who said, “everyone’s in the same boat” (p. 183). For these participants there was an age for women when it was socially permissible to not conform to societal ideas of traditional femininity and accept body changes related to aging (Macia et al., 2015). Since old age may have been characterized as a time of losses of social positions and expectations, the authors surmise that perhaps this viewpoint increased the personal freedom to do what one wants. Thus, the modification of attitude may have been a liberating idea for those women who had deemed themselves less attractive in their younger years to cast off traditional femininity and not perform or adhere to cultural standards set for younger women and westernized society (Macia et al., 2015).

Negative stereotypes also prevailed in the evaluation of older adults’ sex lives as reported in a systematic review of qualitative research (Sinkovic & Towler, 2019). Older adults, including women, were perceived as asexual and therefore may have been excluded from sexual health research (McHugh & Interligi, 2015, p. 89). These perceptions may also have been internalized by older women and impacted their own self-perceptions as sexual beings. The belief that sex in later life is unexpected and disapproved of socially reinforces an asexual older person stereotyping (Sinkovic & Towler, 2019). These pervasive stereotypes shaped public policy agendas and research (Hinchliff et al., 2018).

Sexuality

A complex multidimensional aspect of life, sexuality encompasses biological, psychological and social influences (Baron, 2016). According to the World Health Organization (2016), sexuality is a central aspect of being human throughout the life span that encompasses gender identities and roles, sexual orientation, eroticism,

pleasure, intimacy and reproduction. Sexuality is impacted by social and cultural norms, religious beliefs, body image, self-esteem, sexual dysfunction, pleasure and intimacy. Sexual health has been defined as a state of complete physical, mental and social contentment, not merely the absence of disease or infirmity, in all matters related to the reproductive system (Olsson et al., 2012). Sexual health, therefore, implies that people are able to have a satisfying and safe sex life with the purpose of enhancing life and personal relationships.

Among older adults, the majority believed that quality of life was enhanced with sexual activity as part of a good relationship (Minkin, 2016). Well-being was higher among older adults when they were sexually active (Smith et al., 2019). Postmenopausal women perceived that, for the continuation of sexual activity and satisfaction, the availability of an intimate partner and good physical health were key elements (Harder et al., 2019). Furthermore, in a qualitative study, a sample of older Mexican American women in Los Angeles county, reported that religious devotion was a determinant for sexuality where interest in sexual activity was inversely related to religious devoutness (Lagana & Maciel, 2010). Shame, sin and other religious and cultural aspects affected these older women's sexual activities and the fulfillment of their sexual needs.

Sexuality and breast cancer

Sexuality is an integral aspect of well-being for breast cancer survivors (Ghizzani et al., 2018), but sexuality may be drastically altered by the diagnosis of breast cancer and treatment modalities (Wang et al., 2013). In the case of women who have been diagnosed and treated for breast cancer, both physiological and biological factors may disrupt physical sexual activity and human sexual responses. Older women diagnosed with a very small, early stage breast cancer were significantly impacted with a decline in health-related quality of life in the physical and mental domains (Euhus et al., 2019). The

initial concern regarding a possible diagnosis of a life-threatening illness was complex and potentially impacted the physical domains of sleep patterns, daily activity, dietary intake, and gastrointestinal and cardiac functions (Mehta et al., 2018; Schmidt et al., 2018).

Breast cancer treatment impact on sexuality

A diagnosis of breast cancer and treatments for the disease have the potential to alter the sexual response cycle and function (Soldera et al., 2018). During the early weeks of breast cancer treatment, the loss of sexuality and intimacy were related to fatigue, as sex was a lower priority (Notari et al., 2018). Health care providers presented treatment modalities that focused on overall survival benefit but neglected to share information about short- or long-term influences on aspects of quality of life (Shrestha et al., 2019). The absolute harms, benefits and clinical evidence may have been misunderstood by cancer patients including older breast cancer survivors which promoted poorly informed decision-making by the patient, family member, romantic partner or community which may have placed the breast cancer survivor at risk (Freeman, 2019). Long-term breast cancer survivors as well as their support community including significant others, romantic partners, friends and family members, had misguided hopes, assumptions or beliefs of full recovery and restoration of their pre-treatment life once chemotherapy treatment concluded (Henderson et al., 2019). These perceptions may further confound treatment planning, treatment expectations, decision-making and short- or long-term quality of life outlook. Furthermore, physical and hormone changes secondary to breast cancer treatments may contribute to sexual dysfunction (Ghizzani et al., 2018).

In the following subsection the effects that the main treatments for breast cancer of surgery, chemotherapy, radiation therapy and anti-estrogen therapy may have on sexuality will be reviewed. Then, in the subsequent two subsections treatment side

effects and psychological well-being symptoms such as fatigue, vaginal dryness, anxiety and depression that may influence sexuality among older breast cancer survivors will be described.

Surgery. Surgical procedures for breast cancer occur either as an initial diagnostic modality or as a local curative, neo-adjuvant or adjuvant therapy. All surgical procedures disrupt the integrity of the female breast regardless of the skill, training or qualifications of the surgeon. Once the breast tissue has been biopsied, removed or irradiated, duplication of the original native breast is a challenge (Schwartz, 2019). Sexual problems, including decreased sexual desire and body image disturbance and dissatisfaction, occurred at a higher incidence after mastectomy in women with a low education level who did not undergo breast reconstruction (Manganiello et al., 2011). Women treated with a mastectomy or breast-conserving treatment experienced decreased body acceptance and deterioration in occurrences of intimate relationships with a partner (Jablonski et al., 2018). In an international study, women who underwent breast surgery secondary to breast cancer were at a higher risk of sexual dysfunction than the general population (Streb et al., 2019).

Alterations in breast tissue that influenced sexuality included changes in the symmetry between the affected and unaffected breast, loss of range of motion of the arm on the affected side, lymph edema of the arm and chest wall and loss of breast or arm sensation (Lovelace et al., 2019). Lymph edema of the arm and chest wall deterred sexual satisfaction and interest in breast cancer survivors (Yang et al., 2011).

Contemporary and recent innovations in plastic and reconstructive surgery techniques optimize a more natural and superior aesthetic result. The goal of reconstructive breast surgery is the restoration of a breast mound to preserve the woman’s body image, sexuality and femininity (Cordeiro, 2008). However, according to a recent publication, research regarding a woman’s experience with the initial first look

reaction and psychosocial support available at the event is limited (Paraskeva et al., 2019). In one study, the women found the first look experience moderately distressing along with feelings of loss, shock, despair and decreased femininity. The reconstructed breast for many women was at best a high-grade impostor. Although the reconstructed breast tissue may have been a welcomed transformation and aesthetically pleasing, it never looked, acted or felt like the native or “normal” breast (Kanchwala & Momeni, 2019). The reconstructed breast for some women lacked sensation that affected sexual pleasure and was sexually disappointing and troublesome (American Cancer Society, 2014). Women commonly underestimated the impact of a mastectomy and breast reconstruction on sexuality and frequently cited a need for more information and realistic expectations pertaining to aspects of sexuality (Dikmans et al., 2019). However, despite these challenges, women who had undergone breast reconstruction after mastectomies reported better sexual function, body image and fewer depressive symptoms in comparison to women who received a mastectomy alone (Archangelo et al., 2019). Older women who underwent reconstructive surgery were more likely to receive breast reconstruction with abdominal based autologous flaps and contralateral mastopexy for symmetry (Rodby et al., 2016). The cosmetic appeal of autologous tissue-based flap reconstruction offered older breast cancer patients improved body contouring and an age-matched appearance of the unaffected breast to maintain body habitus (Rodby et al., 2016).

Chemotherapy. Many side effects of chemotherapy have the potential to disrupt sexual function, sexual response cycle or sexuality in women previously diagnosed with breast cancer (Boswell & Dizon, 2015). Potential perceptions of loss of attractiveness secondary to change in hair, skin and nails, and chemotherapy-induced menopausal symptoms potentially contribute to older women’s views of their sexuality and femininity. Not only do women lose hair on their scalp, additional loss of pubic hair, eyelashes and

brows may further impair the older woman's sexuality and her image of self as a sexual being.

Common use of alkylating chemotherapy agents such as cyclophosphamide and melphalan in standard breast cancer treatment regimens has been linked to ovarian failure leading to delayed arousal, diminished orgasm capacity, reduced testosterone levels altering libido, vascular and nerve damage (Metzger et al., 2013). Loss of testosterone has been theorized as one of the key determinants of decreased sexual thoughts, sexual fantasy or erotic fantasy and the interplay of sexual thoughts on an individual's desire and arousal.

Radiation therapy. Current guidelines recommend that early stage breast cancer be treated with breast conservation surgery along with radiation therapy to reduce the risk of local breast recurrence (Kim & Algan, 2019). A woman's quality of life and sexual functioning may be diminished with the associated side effects of radiation therapy of persistent breast pain, arm and shoulder discomfort, loss of flexibility, and lymph edema (Safarinejad et al., 2013). The etiology and relationship between radiation therapy, fatigue, anxiety and depression warrant further research to improve aspects of quality of life for breast cancer patients (Wan et al., 2019).

Anti-estrogen therapy. The clinical standard of care recommendation for women with estrogen positive breast cancer is an anti-hormonal treatment for up to 10 years to deplete estrogen (Burstein et al., 2014). The impact of anti-estrogen therapy on the hormonal milieu is an abrupt onset of menopausal symptoms that impact sexuality (Zhu et al., 2019). Estrogen ablation is associated with bothersome side effects in postmenopausal women such as intense menopausal symptoms including hot flashes, musculoskeletal pain, weight gain, fatigue, depression, dyspareunia, decreased sexual interest, vaginal dryness and altered sexuality resulting in a symptom cluster for some survivors (Zhu et al., 2019). In a recent study, the impact for postmenopausal women

taking adjuvant endocrine therapy for estrogen ablation was associated with more sexual problems, poorer psychosocial quality of life and sexual satisfaction (Dorfman et al., 2019). Higher rates of sexual dysfunction occurred among women treated with aromatase inhibitors, the anti-hormonal treatment typically prescribed to postmenopausal women (Gandhi et al., 2019).

Women 65 years and above described difficulty in differentiating the intolerable side effects related to anti-estrogen therapy from the normal aging processes which delayed support for side effect management (Pieters et al., 2019). Another complicating aspect among older women is that they may have been on hormone replacement treatment to manage menopausal symptoms that was stopped abruptly when the estrogen positive breast cancer was diagnosed (Cohen et al., 2017).

Treatment Side Effects

Fatigue. Cancer-related fatigue is a distressing, persistent, subjective sense of physical, emotional and cognitive tiredness or exhaustion related to cancer or its treatments that is disproportionate to recent activity and interferes with usual functioning (National Comprehensive Cancer Network, 2014, p. FT-1). The differentiating criteria of cancer-related fatigue opposed to normal fatigue experienced after exertion, is feeling tired even when at rest or being unrelieved by rest. Cancer-related fatigue frequently is the most universal and worrisome complaint of cancer survivors during and after cancer treatment (National Comprehensive Cancer Network, 2014).

An astonishing 99% of breast cancer survivors reported they experienced some level of fatigue during treatment (Fox et al., 2019). Among long-term breast cancer survivors, fatigue, reduced cognitive function and sleep disturbance can persist and negatively impact quality of life functions for years following the conclusion of treatment (Schmidt et al., 2018). Because of the fatigue, breast cancer survivors reported that they had decreased sexual intimacy and well-being (Ussher et al., 2012). However, while

cancer-related fatigue can escalate into a wide range of negative effects, many survivors complained that they were not taken seriously when they expressed concerns regarding fatigue (Horneber et al., 2012). Sleep disturbances, including difficulty falling and staying asleep, were reported by up to 80% of breast cancer patients and were found to be a co-morbidity of fatigue (Fox et al., 2019).

Nausea and vomiting. Nausea and vomiting are generally linked, yet can be two separate entities that occur independently of each other. While the prevention of nausea and vomiting was a primary goal established by the National Comprehensive Cancer Network guidelines regarding patients receiving highly or moderately emetogenic chemotherapy regimens (National Comprehensive Cancer Network, 2014, AE-1), 80% of cancer patients reported nausea or vomiting during the course of their disease either because of the cancer itself or secondary to treatment (American Cancer Society, 2017b). In another recent study among women receiving chemotherapy that contained an anthracycline plus cyclophosphamide, nausea and vomiting still occurred in 25.4% of women (De Laurentiis et al., 2018). For the purposes of this review, no publication was found on the impact that nausea, vomiting, or retching can have on psychosocial interaction, self-perception, sexual activity and sexuality.

Hot flashes. Hot flashes, a prevalent symptom for both peri-menopausal and postmenopausal women with and without breast cancer, are commonly expressed as an abrupt onset of warmth accompanied by diaphoresis, or as deemed by an older woman, “my personal summer” (personal communication). The most common risk factor associated with hot flashes in older women was the swiftness of estrogen withdrawal associated with cessation of hormonal replacement and estrogen ablative treatment modalities for breast cancer (Cohen et al., 2017). Breast cancer patients commonly experienced more intense menopausal symptoms than women who underwent natural menopause due to the cessation of hormonal replacement therapy (Cohen et al., 2017).

Hot flashes are complex physiological phenomena in menopausal women. The association between menopause and hot flashes, weight gain, sleep disturbances and mood disorders remain unclear (Ussher et al., 2012). However, evidence was clear that these symptoms had a negative impact on breast cancer survivors' overall quality of life, specifically sexuality (Ussher et al., 2012).

Vaginal dryness. Postmenopausal women with vulvovaginal atrophy associated with decreased estrogenization of the vaginal tissues had a 3.84 higher probability of developing female sexual dysfunction difficulties with sexual desire, arousal and orgasm, dysparenia and urinary incontinence (Pitsouni et al., 2018). Among postmenopausal women treated for breast cancer, the prevalence of vulvovaginal atrophy was found to be 61.5% (Crandall et al., 2004).

Hypoactive sexual desire dysfunction was more common in partnered community-dwelling older women with dysparenia, symptomatic pelvic floor dysfunction and was associated with significant sexually related personal distress (Zeleke et al., 2017). Vaginal dryness, dysparenia or the pain encountered when vaginal penetration was attempted could result in a decrease or loss of sexual desire (Sadovsky et al., 2010). Only 25% of women with vulvovaginal atrophy received adequate therapy for symptoms (Naumova & Castelo–Branco, 2018). Women with vaginal dryness reluctantly resumed sexual intercourse due to marital duty and fear of abandonment if they did not resume sexual activity with their romantic partners (Santos et al., 2017). The ensuing implication for older breast cancer survivors experiencing vaginal dryness was the potential inability to become aroused and achieve orgasm, and relax and enjoy sexual intercourse with a romantic partner.

Urinary incontinence. Urinary incontinence was found to be a common phenomenon with an estimated 25 million Americans suffering from incontinence or the complaint of involuntary loss of urine (Abrams et al., 2010). Epidemiological studies

indicated that 51% of older women are disproportionately affected by urinary incontinence symptoms compared to 19% of men (National Committee for Quality Assurance, 2019). For postmenopausal breast cancer survivors, urinary incontinence was a significant predictor of sexual dysfunction (Greendale et al., 2001). Unfortunately, urinary incontinence is often assumed to be merely an inevitable consequence of growing older.

Cardio-respiratory symptoms. Postmenopausal women who were successfully treated for breast cancer sustained long-term cardio-respiratory toxicity risk secondary to chemotherapy, radiation therapy and aromatase inhibitor treatments that emphasized the importance of cardiotoxicity management for these survivors (Mehta et al., 2018). Cardiovascular and pulmonary diseases have been shown to have a significant negative impact on sexuality in the older adult population (Tetley et al., 2018). Given that the general public views the non-coexistence of heart disease and sexuality or the limitation of sexual acts due to perceived risk of myocardial infarction, the impact of cardiovascular disease on sexuality may be profound (Steptoe et al., 2016). Fears of angina or myocardial infarction and decreased stamina related to shortness of breath or hypoxia led to an inability to participate in sexual activities, along with dyspnea or angina on initiation of sexual stimulation. Fears such as these led older women and their partners to believe that sexual activity is over for them, which impacted their sexual self-perception and expression (Tetley et al., 2018).

Psychological Well-Being

Anxiety and depression. Prevalence of anxiety and depression in women after breast cancer treatment was 32% and 38% respectively (Tsaras et al., 2018). An analysis of community-dwelling older breast cancer patients in primary care practices in Germany indicated that older women were at significantly higher risk levels of 1.2 for the development of depression and anxiety compared with younger women (Engelhard et

al., 2015). In a study conducted in the Netherlands women age 70 years and above reported enjoyment in the participation of social activities with other breast cancer survivors where the subject of breast cancer rarely came up, but explicitly stated they did not want to attend or talk to a room full of strangers in a support group setting (Van Ee et al., 2019). Older survivors of invasive early stage breast cancer in another recent study also reported negative assumptions regarding support group activities of emotional support as negative space where “old women sit around crying” (p. E4) which was deemed non-beneficial and as a situation to be avoided (Green et al., 2018).

Depression has a global influence on the way individuals experience the world around them and negative effects on sexual function in women (Fabre & Smith, 2012). The condition of depression is more frequently diagnosed among older women age 55 years and above at 7.5 % compared to males 5.5% according to the latest World Health Organization (2017) report. Prevalence of depression and mood disorders in cancer survivors in a recent literature review has been estimated as high as 60% (Caruso et al., 2017).

In a study of partnered breast cancer survivors, depressive symptoms and vaginal dryness had direct detrimental effects and alterations on sexual functioning for sexually active and inactive women (Avis et al., 2018). Additionally, the sexually inactive participants of this study were older and reported more depressive symptoms along with a decreased self-perception of attractiveness and satisfaction with sex life.

Treatment of depression had a major effect in improving the overall perception of life of women subsequent to a diagnosis of breast cancer (Blanco et al., 2019). However, while depression can be effectively treated with oral medications, many anti-depressants potentially impact sexuality negatively. Specifically, anti-depressant medications potentially impair desire, orgasm, libido, arousal and other components of sexuality that influence expression, thoughts or behavior (Dording & Boyden, 2019, pp. 123-124).

Altered body image and self-esteem. Body image and self-esteem encompass the integration of the physical, psychological and social dimensions of sexual existence or overall wholeness of the individual. The loss of a breast for women due to breast cancer may negatively impact body image, feeling that “a part of my body is nonexistent” (Kocan & Gusoy, 2016, p. 147). Body image problems along with the negative impact on psychosocial outcomes of sexual and physical attractiveness persisted for up to twenty years after breast surgery in women with bilateral mastectomies for risk reduction of breast cancer (Bai, et al., 2019). In another recent study women in South Africa treated for breast cancer whose self-esteem was anchored in physical appearance were at a higher risk for greater psychological distress (Schlebusch & Van Oers, 2019).

Fear of rejection by romantic partner. Fear of rejection by a romantic partner due to the perception of loss of attractiveness and poor body image secondary to alopecia, skin changes and breast tissue changes caused additional distress for women subsequent to the diagnosis of breast cancer (Boing et al., 2019). The summation of these changes resulted in feelings of being rejected, withdrawal, isolation, sadness and possible diminishment of sexual attraction or desire (Almeida et al., 2012). Some male romantic partners had reported feeling fearful of engaging in honest direct discussion regarding sexual intimacy, body image changes and personal sexual need gratification due to an overwhelming fear of causing emotional pain to the breast cancer survivor (Canzona et al., 2019). Breast cancer survivors may have misinterpreted actions of partners as perceptions of repulsion from romantic partners. In a qualitative study the spouse of a breast cancer survivor described a misunderstanding about perceptions about sexuality and body image by both partners (Sheppard & Ely, 2008). The husband later realized a sufficient period of time was necessary for his wife to heal from the events of surgery, requiring the postponement of sexual activity. In a systematic review of the literature, it was concluded that there was insufficient literature on the effect of a

supportive partner's role on the recovery processes of mastectomy and reconstructive surgery (Rowland & Metcalfe, 2014).

Resuming sexual activity for older women who have undergone surgery for breast cancer may be a daunting task. In one study 50% of women after breast surgery for cancer were not sexually active three months after their surgery, and 42% reported no interest in sex (Quitard et al., 2014). Younger age was the most influential predictor for higher sexual functioning (Quitard et al., 2014). A recent study of the attributes of sexual activity among breast cancer survivors aged 24 to 70 years old (mean=49, SD=12.26) who were in heterosexual relationships, self-confidence was required for the women to engage in satisfactory sexual activity (Canzona et al., 2019). However, diminished self-confidence after a breast cancer diagnosis and treatment challenged sexual functioning leading to decreased sexual satisfaction and engagement (Canzona et al., 2019). Breast cancer survivors theorized that the pain experienced during intercourse decreased their partners' initiation of other forms of sexual intimacy (Canzona et al., 2019).

Personal relationships. Human beings need intimacy, a feeling of belonging within social interaction. In a sample of older women, the perception of oneself as a sexual being was often expressed as a bond with another individual and the explorations of other forms of expression through the sexual energy of art, food, music, dancing and motherhood (Stahl et al., 2019). Women diagnosed with breast cancer related and reconnected with their partners through intimacy and sexuality (De Boer et al., 2019). However, the perceptions of post-treatment bodily changes acted as obstacles to addressing the sexual and intimacy needs, thoughts, and feelings of the cancer survivor and her partner (Canzona et al., 2019). As a result, the couples were uncertain about initiating candid conversations about sexuality, which inadvertently perpetuated a cycle of silence. Thus, the influence of the diagnosis and treatment on intimate relationships

resulted in additional marital stress. Conversely, partner support had a significant role in the preservation of sexual function, sexual quality of life and body image for women previously diagnosed with breast cancer (Kowalczyk et al., 2019). Supportive intimate partners served a pivotal and influential role in the decision-making and coping processes that occurred subsequent to a mastectomy in the consideration of breast reconstruction (Lamore et al., 2019).

The influence of community advisors can perpetuate misconceptions about sexual activity for breast cancer survivors. Researchers in China found that the “elderly women” (p. 4) of the community advised breast cancer survivors to abstain from sexual activity after a diagnosis and treatment of breast cancer from fear that “it will lead to the recurrence of the disease” (p. 4) (Wang et al., 2013). The outcome of adherence to such advice resulted in a decrease in or absence of marital sexual activity, which negatively impacted these Chinese women’s marital relationships leading to marital distress and potential divorce.

Isolation, abandonment and loneliness. The desire to alleviate loneliness, isolation and feelings of abandonment is a primal drive for both physical and emotional well-being throughout the life span (Rokach, 2019, pp. xi-xiii). Older adults may experience loneliness, depression and inactivity that lead to adverse physical and psychological health consequences (Krause-Parello et al., 2019). Due to the changing health care environment of managed care and the Affordable Care Act, women 65 years and above may have felt an increased sense of abandonment related to limited follow-up care provided by oncology specialized providers (personal communication with my gerontology patients). Women were required to follow-up with primary health care providers who may have been ill equipped to identify, diagnose or address long-term side effects of breast cancer treatments, especially sexual concerns (Wallner et al., 2019). Only one in three primary care providers reported discussing treatment options

with women newly diagnosed with breast cancer, while 22% felt uncomfortable and 17% recognized they did not possess adequate knowledge to participate in treatment decisions (Wallner et al., 2019). Additionally, primary care providers cited lack of education and training for follow-up survivorship care for breast cancer survivors (Radhakrishnan et al., 2019). In a recent publication set in the US, it was concluded that research is needed to identify the role of primary care providers subsequent to the diagnosis of breast cancer (Wallner et al., 2019).

Sexuality conversations in clinical settings

Despite the fact that sexuality is an essential component of well-being, discussions about sexuality continue to evade the oncology clinical setting (Fitch, 2018). This finding is especially alarming because sexuality was found to be one of the greatest social concerns for cancer survivors (Schover, 2018). Women frequently cited their desire for sexual consultation, but breast cancer survivors identified few physicians or nurses who gave sexual advice with the exception of avoidance of pregnancy (Wang et al., 2013). When these conversations did occur, they often centered on healthy young heterosexual individuals.

Existing cultural stereotypes can influence both patients and providers. Older women may have been excluded from sexuality discussions due to stereotypes of sexually active older individuals as deviant representations of being dirty old men or sexy seniors (Estill et al., 2018). The myths surrounding aging and sexuality may also contribute to the belief that sex and intimacy were exclusively for younger adults (Minhat et al., 2019). Breast cancer survivors were reluctant to voice sexual needs or concerns in spite of their significance (Ghizzani et al., 2018). Older women were also hesitant to discuss issues of sexuality and intimacy with health care providers due to generational beliefs that the obligation rested on the health care provider to initiate this sensitive topic (Yee, 2010).

Many oncology nurses perceived sexuality discussions as taboo (Jung & Kim, 2016). Oncology nurses were aware of the need and importance of sexuality discussions with cancer patients and their romantic partners to address the sexual changes that may have occurred as an outcome of the cancer diagnosis and treatment (Fitch, 2018). However, regrettably for women with a history of breast cancer many health care providers, including highly specialized oncology nurses, were uncomfortable or reluctant to perform the detailed evaluations and intervention techniques requisite to identify and manage sexual issue concerns (Manganiello et al., 2011). Sexuality discussions occurred infrequently due to lack of knowledge about sexuality, fears of giving misinformation, hoping someone else would provide the information and lack of time (Olsson et al., 2012). Consequently, the sexuality needs of breast cancer survivors, including the large group of women 65 years and older, subsequent to the diagnosis of breast cancer were potentially not acknowledged or addressed. Older breast cancer survivors routinely received a precautionary warning which states penetrative intercourse should be avoided during chemotherapy treatment when platelet and neutrophil counts were low (Kelvin et al., 2014). This limited counseling left major questions of intimacy expression or sexuality unanswered.

Hence, there remains a gap between the sexuality needs of the breast cancer survivor community and the response of health care providers. Breast cancer survivors' sexual needs were often unattended or inadequately addressed by health care providers (Male et al., 2016). Improvement strategies outlined for the oncology health care team members by the National Comprehensive Cancer Network published in 2014 suggested availability of education and training to identify sexual health needs, sexual dysfunction, management strategies and the resources available to enhance outcomes of sexual health in the population of older breast cancer survivors (Denlinger et al., 2014). Although strides continue to be made, there persists a lack of knowledge, understanding

and intervention strategies aimed at older breast cancer survivors' specific sexuality needs.

Femininity

For the purposes of this literature review, femininity was approached as a complex social construct that encompasses gender identity, the development of feminine identity, the task of measuring up to the feminine ideal, breast reconstruction decisions and self-assessment of femininity for the breast cancer survivor. Additionally, femininity is a complex concept embedded within the constructs of aging and sexuality.

Gender identity. Gender is socially constructed as to what constitutes the characteristics of being masculine or feminine (Hollander et al., 2011). Femininity is a contextual concept that relates to behaviors, expressions and actions that are viewed as varied as the number of individuals in a society. The significance of gender typicality for cisgender adults impacted the psychological well-being for adults residing in the US; women with strong gender identity possessed enhanced self-esteem (Tate et al., 2015).

Femininity has been defined as whatever society promotes as feminine, learned and understood through traditional practices of femininity and beautification (Furman, 1997, p. 2). Feminist writers and researchers have tried for decades to fully illuminate this elusive concept. Gender, a perpetually evolving concept, allows for uniqueness in the expression of personal identity. Femininity is a culturally constructed phenomenon closely linked to society's visual images in magazines, movies, television, advertisements, literature and social media. As identity is a key element of an individual's subjective reality (Berger & Luckmann, 1966, p. 174), a conflict in femininity may arise or become apparent subsequent to the diagnosis of breast cancer in the way women view themselves in opposition to conventional or traditional feminine gendered behavior, actions, traits or expressions.

Development of feminine identity

Feminine identity may be seen as the quest of a woman for self-definition. The perpetual question a woman poses to herself is, “Who am I?” Erik Erikson (1968) contends that a sense of identity is the most important accomplishment of late adolescence, which prepares a woman for adulthood. A sense of uniqueness enables the individual to organize all past and present experiences, characteristics, desires and orientations into a consistent and cohesive symbol of self in the scheme of life and worldview. Identity can potentially be fragile, and if disrupted, the individual may experience an identity crisis (Lichtenstein, 1980). An important note for these interpretations is that both Erikson and Lichtenstein were male gendered identity authors who viewed femininity in the context of their times.

Seminal work from the 1970s contended psychology identity theory development had been dominated by a male-centered academia, noting women were essentially excluded from research as participants or investigators (Belenky et al., 1997). Women were inclined not to pursue a profession in the sciences, and even the model of female academia was a replica of male academia. Further, women struggled with societally engrained definitions of femininity, feminine identity and womanhood. The importance of the intertwinement of women’s self-concept and ways of knowing truth and knowledge must not be overlooked in the pursuit of research (Belenky et al., 1997). The significance of investigation of women from the perspective of women for further knowledge development cannot be underestimated (Belenky et al., 1997; Rodgers, 2005). One female scholar annotated the importance of female gender as an element for shaping knowledge as well as constructing individual experiences (Rodgers, 2005, p. 161). Thus, to understand feminine identity or femininity preservation after breast cancer, investigation must focus on the perspective of women to hear female voices.

Significance of female breasts

Female breasts are recognized as the ultimate symbol of femininity and one of the most significant physically discernible characteristics of erotic beauty across cultures (Schlebusch & Van Oers, 2019). Breasts are equated as a source of nourishment of babies and small children, and as organs of sexual attractiveness or pleasure. For breast cancer survivors after mastectomy, the surgically removed breast represented femininity, motherhood and beauty (Kocan & Gursoy, 2016). In another study the disfigurement from losing a breast resulted in a discrepancy between the self and societal expectations of being a woman and femininity (Sun et al., 2018). Physical changes from altered breast appearance had a long-lasting impact that affected the women's self-image with feelings of mutilation, unattractiveness, being inadequate or less feminine (Boquiren et al., 2016). Older women may have a poor body image associated with their breasts prior to the breast cancer diagnosis. Regrettably, for the purposes of this review, no baseline statistics on the topics of contentment with body image, self-esteem and femininity of older women prior to breast cancer were found.

Measuring up to the feminine ideal

Body image was a substantial and integral element of the way women diagnosed with breast cancer conducted a self-evaluation and constructed a sense of femininity and attractiveness (Barel-Shoshani & Kreiter, 2017). Women's beliefs that influenced the choice to undergo breast conserving surgery encompassed body image and femininity (Gu et al., 2017). Older women benefitted from conservative breast cancer treatment in enhancement of body image, femininity and quality of life. Positive outcomes of lumpectomies, which preserve the breast tissue, gave a preferred aesthetic result compared to a mastectomy in older women (Ugolini et al., 2019, pp. 104-111). Despite evidence that older women benefitted from less radical surgeries, surgical procedure differences continue to exist with the higher incidence of mastectomy rates among older

women (Frebault et al., 2019). In a review of influencing factors on early stage breast cancer decisions to undergo mastectomy versus breast conserving surgery, findings indicated that older women with lower socioeconomic status and a male surgeon were more likely to undergo a mastectomy (Gu et al., 2017).

Breast reconstruction decisions

Preservation of a woman's body image with immediate reconstruction of the breast tissue had been established as a surgical modality to enhance femininity and decrease emotional distress after a mastectomy (Cordeiro, 2008). Some women initially declined or deferred reconstruction decisions to after chemotherapy and radiation treatment had been completed. Despite the advantage of breast reconstruction to femininity and the psychological and emotional benefits endorsed by the American Cancer Society (2013), not all women were content with the results. Disappointment ensued due to unrealistic expectations of breast appearance and comparative differences between the native and reconstructed breast, along with lack of sensation of reconstructed breast (American Cancer Society, 2013).

In one qualitative study of 30 women from a support group aged mid-thirty to mid-seventy with an average age of 54 years, the participants were given a detailed lecture on breast reconstruction by a local plastic surgeon (Clark, 2017). During reconstruction lectures the women were shown photographs or visual depictions of the ideal breast with measurements and descriptions of being round and perky (Clark, 2017). Pictures of poorly or not fully healed mastectomy scars were also shown as a comparison to the reconstructed breast to influence the decision-making process of the potential reconstruction candidate. The impact of visions of more youthful breasts for an older woman led to an unrealistic expectation of surgical outcomes, leaving the woman disappointed and dissatisfied (Clark, 2017). The lecturer reassured the women of the group the importance of personal choice in the decision-making process of

reconstruction, yet implied the non-pursuit as a possible mistake describing how a daily shower or clothing change would be a continuous reminder of the lost breast (Clark, 2017). Additionally, some of the women shared incidents during plastic surgery consultations of feeling pressured to wake up with a “normal” (p.34) body by the plastic surgeon who told the woman, “You don’t need to think about it. Just do what I’m telling you to do, before you change your mind” (p.34). Thus, the women received contradictory information regarding personal choice decisions about breast reconstruction.

Self-perception and demonstration of femininity after breast cancer diagnosis

The use of self-figure drawing was found to be constructive as a tool to evaluate changes in women’s self-perception of femininity after the diagnosis of breast cancer. Sketching a self-portrait employed fewer defensive mechanisms than verbal descriptions that enabled a spontaneous expression of one’s inner world (Barel-Shoshani & Kieter, 2017). In a study conducted in Poland, the researchers found that women treated with a mastectomy or breast conserving treatment paradoxically scored higher in manifesting femininity as a compensatory mechanism for mutilated womanhood to reconstruct self-esteem (Jablonski et al., 2018).

“Pinkification” (p. 603) by the breast cancer community has been seen as an attempt to create a persuasive hyper-feminine facade of the breast cancer diagnosis along with the normalization of breast reconstruction after a mastectomy (La et al., 2019). However, not all breast cancer survivors desire to undergo breast reconstructive procedures for femininity and body image contentment. From a thematic and feminist analysis of on-line posts on a women’s breast cancer forum, some women chose to forego breast reconstruction in the negotiation of normative femininity to exist as “flat and fabulous” (La et al., 2019, p. 603).

Based on the limited research found for this review, the construct of femininity in the population of women aged 65 years or above subsequent to breast cancer is

underexplored and underrepresented in the current state of science. The meaning and impact of breast tissue loss, surgical reconstruction of the breast tissue and the self-perception of femininity in the unique population of older breast cancer survivors remain unknown. Additionally, it is unclear whether age-specific assessment and information concerning femininity is tailored to the distinctive needs of older women in oncology clinical settings. Consequently, older women's specific needs, beliefs and experiences related to femininity after the diagnosis of breast cancer are limited.

Discussion

The purpose of this literature review was to understand the state of the science on sexuality and femininity among women 65 years and older subsequent to a diagnosis of breast cancer. Minimal data exist regarding the experiences and the journey that women aged 65 and above take to preserve sexuality and femininity after diagnosis and treatment of breast cancer. Sexuality is a vital component of existence, and femininity, also an essential aspect of being human, is a complex concept embedded within the constructs of aging and sexuality. Yet, the lack of research on sexuality and femininity in breast cancer survivors aged 65 years and older is glaringly obvious.

While normal aging affects the expressions of sexuality and femininity, aging is highly individualistic and thus influences older women in distinct ways. Common age-related stereotypes and cultural expectations influence self-perceptions of advancing age, which are possible challenges for breast cancer survivors subsequent to diagnosis and treatment.

Sexuality can be negatively affected by treatment modalities and side effects for breast cancer. Psychological well-being can be disrupted by anxiety and depression with alterations in self-esteem and body image along with the detrimental impact on personal relationships. Conversations in the oncology care setting regarding sexuality continue to be scarce, leaving the sexual care needs of older breast cancer survivors unmet.

Femininity among older women who have been treated for breast cancer is an unexplored area of research. The significance of the female breast is culturally and personally the ultimate symbol of femininity for many women. Consequently, the loss or change of breast tissue integrity can potentially hasten a perceived change to femininity.

As an outcome of the potential challenges to sexuality and femininity among older breast cancer survivors, the task the health care providers and survivors share is the alleviation of long-term consequences of the diagnosis and treatment. Hence, the collaborative focus needs to progress to living beyond the breast cancer diagnosis and treatment outcomes for older women including the expression of sexuality and femininity.

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Chapter 3

Philosophical Underpinnings and Theoretical Perspectives

To ensure a strong investigative theoretical framework, researchers must choose philosophical paradigms congruent with their beliefs about the nature of reality (Mills et al., 2006). The intent of this chapter is to trace the historical origin of the philosophical and theoretical foundations that informed this dissertation. I will examine the contributions of Charles Darwin, George Herbert Mead and Herbert Blumer toward the formulation of symbolic interactionism. The philosophies of Darwinian evolution of the world as dynamic opposed to static, Mead's development of self and Blumer's use of symbols and language will be summarized as applied to this research. In addition, social constructivism, another important philosophical underpinning of the study, will be reviewed. Unexamined assumptions increase the risk of research bias. Therefore, my assumptions before and during the research process will be examined as social constructivism dictates that the interaction of the participants and researcher results in the construction and understanding of reality as meaning emerges from life events (Charmaz, 2014, p. 14). In conclusion, since qualitative descriptive was an integral part of the analysis, the conceptual underpinnings of the method will be described.

Philosophical Influences on Methodology and Method

Darwinism

The publication of Charles Darwin's *On the Origin of Species* in 1859 can be acknowledged as an historical event for scientific thinking. Having both a scientific and philosophical impact on thought and investigation, Darwin's juxtaposed worldview of the universe not as a static entity, but a dynamic interactive milieu served as the founding premise of his theory of evolution. The Darwinian evolutionary approach to questions identified the interaction of elements in the environment, which shape the species, entity or being. Like species, individuals are capable of infinite adaptation in which beneficial

traits enhance survival. The active interaction between the elements of the environment and the entity are of utmost importance in creating a gradual transition or adaptation of individuals or species.

One powerful implication of Darwin's evolutionary theory, which influenced this research, is the premise that encountering elements of the environment does not lead to a known set of conclusions. The outcomes of the encounter are unpredictable and cannot be determined by mathematical formulae or deduced by knowing the set of elements and the entity involved. This supports the notion of a gradual transition, not a radical transformation, in adaptation over time.

Darwin's theory of evolution paved new pathways for scientific inquiry. Instrumental and pivotal, this evolutionary theory greatly influenced theories of development of self, symbolic interactionism and social constructivism. An example of a further development is that the constant dynamic process of adaptation, modification and unpredictability central to Darwinism was subsequently taken further by social constructivism.

Symbolic Interactionism

Symbolic interactionism's principal founder, George Herbert Mead, postulated the social nature and origin of self when he was a social psychologist at the University of Chicago and member of the school of pragmatism (Charon, 2010, pp. 24-25). Mead's interactionist theory proposes that human beings define self through social roles, expectations and perspectives cast on self by society and its members (Annells, 1996). Both Mead and Darwin regard human development as a continuous, dynamic evolutionary process. Foundationally, humans are part of the animal world with the added uniqueness of a highly developed brain and the ability to develop and utilize a language system. These unique characteristics facilitate in humans the ability to reason and interact not only with the environment and others but also within themselves. This

privileged engagement with oneself, others, society and environment sets humans apart from all other members of the animal kingdom. As such, humans are not passive beings created or controlled by the factors surrounding them in their environment. Instead humans are active participants shaping and constructing their destinies through interaction, making choices and acting according to their perceived opportunities, meaning and consequences within the milieu of life. A constant dynamic process of evaluating situations allows for purposeful action, which negates the notion of a haphazard view of life. Symbolic interactionism also states that meaning is the central theme of human existence and permeates each moment, action and consequence. Humans evaluate every perceived element of life and give it meaning. Individuals are in a constant process of change, reassessing actions, thoughts or notions, always in a dynamic state of becoming (Charon, 2010, p. 114).

Herbert Blumer, a student of Mead, further advanced the concepts of his teacher in constructing symbolic interactionism. Consistent with Mead's concept of self, Blumer views humans as contributing to the construction of self exclusively through social interaction, contingent on language and communication (Charmaz, 2014, p. 9). Blumer formulated three basic premises (Blumer, 1969, p. 3). First, the meaning of things for individuals will determine the action taken toward those things. Second, meaning is derived from social interaction. Lastly, an interpretative process is utilized to direct and modify the meaning as the situation is analyzed and acted upon by an individual. These dynamic processes are in constant states of re-evaluation and interpretation by the individual. The subsequent response made to the situation, environment or elements is not merely a reactionary response. Rather, human responses reflect an adjustment grounded in meaning and interpretation of the environment.

Blumer's ontology of symbols is the key foundation of symbolic interactionism. Language, an important symbol, is an instrument to derive understanding and meaning

from what our senses experience as the essential core of social life expression. Thus, language enables human beings to observe and understand how other people perceive reality, create meaning and take action. As such, symbolic interactionism served as a vital philosophical underpinning in this research with the purpose to explore and understand events such as breast cancer, sexuality and femininity in the lives of older women with the words of the women themselves.

Essential tenets of symbolic interactionism focus on the nature of self and taking on the role of the other. This intentional and meaningful act enables successful communication and interaction within society (Charon, 2010, p. 109). For a qualitative researcher such as myself, taking on the role of the other is a theoretical core element of being human.

Social Constructivism

The post-modern era saw the development of social constructivism. A primary tenet of the paradigm is the value of deconstructing assumptions, knowledge and bias, with the reconstruction of meaning and understanding (Polit & Beck, 2016, pp. 10-11). According to this philosophical viewpoint, the world of everyday life is humankind's fundamental and paramount reality (Schutz & Luckman, 1973, p. 3). An individual's experience is embedded in the interaction of self, others and the world during the construction of meaning. Mind and body cannot be separated from the construction of knowledge through one's experience (Lock & Strong, 2010, p. 49). The interpretation, acceptance and legitimization of reality are continuous processes of creation and re-creation of expectations through social engagement with self, others and the environmental milieu. Thus, social constructivists view the emergence of knowledge through discovery of meaning in the social world of individuals (Charmaz, 2014, p. 14).

Qualitative Descriptive

The qualitative descriptive method strives to study phenomena in a non-manipulated state of existence to maintain a naturalistic inquiry stance. A qualitative descriptive design lends itself to be the least encumbered by theoretical and philosophical commitments compared with other qualitative methodologies such as phenomenology, grounded theory or narrative studies (Sandelowski, 2000, p. 337). Nevertheless, the assumption prevails that all researchers possess and employ conceptual, theoretical and philosophical appraisals of data and findings. Hence no study, including qualitative descriptive, is conceptually naked (Sandelowski, 2010, p. 79). Utilization of theoretical, philosophical and conceptual approaches from other qualitative methodologies is often employed in the qualitative descriptive research process from study conceptualization through data analysis. Lastly, although the focus of qualitative descriptive is the portrayal of a participant's life event in rich descriptive language, the obligation of interpretation of findings serves to advance the state of science.

Philosophical Influences on this Dissertation

Darwin's continual scholarship and contemplation throughout his life pioneered numerous essential skills for the qualitative researcher. As the principal investigator my task was to trace overarching elements in the lives of a sample of older women to illuminate the meaning, adaptation and modification of sexuality and femininity in their daily lives subsequent to the diagnosis of early breast cancer. Akin to Darwin's work, this research emphasized the active interaction of the participants with their environment, which resulted in gradual change or modification. The importance of adaptation is that it is beneficial to the successful survivorship of the individual.

The significance of Blumer's work to this investigation is the acknowledgment that one's responses are not reactionary but grounded in interpretation and meaning. Thus, for the women of this study the diagnosis of breast cancer does not have creative

control or power of modification, which can be predicted by a known set of variables. Rather, the individual interacts with her symbolized perception of the breast cancer trajectory to create meaning in her worldview of sexuality and femininity.

Viewing the participants and myself as actors interacting was a vital component of this co-constructive research process. It was essential to continuously examine my preconceptions and assumptions regarding the essential components of the study: women aged 65 years and above, breast cancer, sexuality and femininity. Taking the role of the other was pivotal for me with the requirement to transcend my own viewpoint and assumptions to enter into the participants' vantage point of subjective reality. To find meaning, I needed to focus on the complex interrelationships that create the structure of reality, the interaction of symbols, environment, and thought that shaped the participants' perceptions and worldviews (Lincoln & Guba, 1985, p. 58). Individual elements could not be separated from each other but were inextricably intertwined with significance and meaning. Each woman in the study had her own reality and life experience surrounding the diagnosis and treatment of the cancer. As the principal investigator, I was not able to predict the numerous perceptions and themes that would arise from the interviews with the participants. Instead, it was essential in the investigative process to allow the narratives to unfold with the emergence of personal meaning. Furthermore, due to the multifaceted nature of sexuality and femininity each participant had her own reality based on the interplay of physical, psychosocial and contextual complexities. The investigational pursuit of the study was to understand the meaning, reconstruction and adaptation of sexuality and femininity subsequent to the diagnosis of early breast cancer and treatment.

In conclusion, the unique philosophies of Darwinism, symbolic interactionism, social constructivism and qualitative descriptive have informed and shaped my actions as an agent of inquiry. I recognize the influence of the chosen frameworks to drive

decisions in the investigational design, data collection and the data analysis in regards to sexuality and femininity for women 65 years and older subsequent to the diagnosis of breast cancer.

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CHAPTER 4: Research Design and Methods

The intent of this chapter is to describe the research design and procedures including data collection, analysis and management, as well as the ethical considerations deployed in the study. The primary research design in the study was a qualitative descriptive method (Sandelowski, 2000; Sandelowski, 2010) informed by the principles of constructivist grounded theory (Charmaz, 2014). This qualitative approach served to illuminate key elements of sexuality and femininity among a sample of women 65 years or older who had been treated for early stage breast cancer in rich descriptive language.

Research Design

Qualitative research designs accommodate complex social perceptions that are not easily measured or understood and require thoughtful exploration. As such, qualitative designs seek to capture and understand the intricate relationships of components in the context of an event, setting or time (Corbin & Strauss, 2015, p. 155). Fundamentally, qualitative approaches are grounded in the holistic epistemology that recognizes and values both the singularity and pluralism of a reality as credible investigational conclusions (Charon, 2010, p. 3). Accordingly, study findings of variation and regularity are regarded as having the same value of significance. Furthermore, qualitative research design allows for the study of endless possibilities of the human response and its complex relationships as the methodologies acknowledge the dynamic process of the way perceptions are formed or transformed by the events of life (Corbin & Strauss, 2015, p. 5). Hence, a qualitative research design was deemed most appropriate to explore the inner experiences and perceptions of older women surrounding sexuality and femininity because these two complex concepts have not previously been fully researched in the population of women aged 65 years or older subsequent to a diagnosis of breast cancer.

Qualitative Descriptive Method

For this dissertation, qualitative descriptive inquiry was the method used to capture the dynamic interactions of participants' experiences, expertise and perceptions contributing to the overall understanding and interpretation of life subsequent to the diagnosis of breast cancer. The purpose of a qualitative descriptive design is to generate descriptive, individual and plural data that is utilized to understand how individuals act and make sense of their world (Corbin & Strauss, 2015, p. 12). This task necessitates the capture of rich descriptive portrayals of participants' significant life events. Furthermore, as all inquiry encompasses elements of interpretation, the qualitative descriptive method enabled the investigators to move beyond simple description (Sandelowski, 2010).

Constructivist Grounded Theory

Constructivist grounded theory (Charmaz, 2014) served as a methodological framework to organize, gather and persistently develop the analytical processes compulsory to this qualitative inquiry. The methodology requires ongoing interaction with the data to acquire a richer description, understanding and appreciation of the participants' perceptions of their lives. Hence, knowledge of the research phenomenon is co-constructed throughout the interactions during the interviews and systematic analytical processes of the study. As per the systematic guidelines in constructivist grounded theory, personal and analytical memos were written about the data as it emerged (Charmaz, 2014, p. 162). These new insights challenged assumptions and preconceived realities of the principal investigator that she had accumulated over years of practice as an oncology nurse practitioner. Additionally, these memos and ongoing discussions with my chair led to the development of myself as a constructivist grounded theory researcher.

Symbolic interactionism (Charon, 2010), a philosophical approach that underlies grounded theory, enabled a richer understanding of the subjective meaning and significance of events in the participants' social worlds. Viewing the participants and myself both as part of a dynamic assemblage of actors interacting to distinguish significance and meaning served as a vital component in the research process. This stance enabled understanding of the human behavior, actions and thought processes both within the participant and between the woman and other people. Analysis of these interactions allowed for the emergence of a diversity of perspectives.

Data saturation is established when no new categories are emergent in the data and the complexity of identified categories demonstrates dimensional variation (Corbin & Strauss, 2015, pp. 139-40). Acquisition and accomplishment of theoretical sufficiency is an imperative element of data saturation and thematic corroboration (Marshall & Rossman, 2016, p. 229). Theoretical sufficiency asserts that the iterative process of analyzing new and established data themes concurrently tests the research findings for substantiation and dimensionality to conclude data procurement (Marshall & Rossman, 2016, p. 229; Given, 2016, p. 135). Data saturation is not required for a qualitative descriptive study as opposed to grounded theory methodology. The reason for this difference is that with qualitative descriptive inquiry, data are gathered into a comprehensive summary of an event (Sandelowski, 2000) while grounded theory methodology requires nuanced data, i.e. saturation, to move up to an explanatory framework with categories and subcategories grounded in rich data. For the purpose of this dissertation, a qualitative descriptive method vividly delineated the details, senses and emotions subsequent to the breast cancer diagnosis based on the descriptions with 19 participants, but the data did not adequately meet the requirements for data saturation. Thus, while the interviews were conducted using constructivist grounded theory methodology, data collection was stopped before saturation was achieved. The

reasons for this decision were based on the fact that despite many attempts to recruit in various ways over years, few women volunteered. Henceforth, after discussions with my chair and agreement from the members of my committee, the pragmatic approach of a qualitative descriptive method that does not require data saturation was engaged in the exploration of life subsequent to the diagnosis of breast cancer in women aged 65 and above.

Protection of Human Subjects

The South General Institutional Review Board (IRB) at the University of California, Los Angeles, reviewed and approved the study proposal and all protocol-related materials for recruitment and data collection prior to any enrollment or accrual of participants. The principal investigator, faculty sponsor, and transcriptionist were all certified in the Health Insurance Portability and Accountability Act, which insured confidentiality of health information. Additionally, immediately after the interview each study participant was assigned a study number and pseudonym, which was kept in a locked cabinet with access only available for myself. All strategies for the protection of confidentiality of the study participants were employed throughout the course of the study.

Written Informed Consent Procedure

I reviewed details of the study purpose and time commitment with the potential participants who called to volunteer for the study. Each participant was informed that an interview would be scheduled to have a conversation about her perceptions and experiences surrounding the breast cancer diagnosis and treatments, femininity and sexuality.

When we met for the interview, the potential participant was given the opportunity to review the consent form and ask any questions she may have had about the study. Considerations for age-related visual and hearing sensory changes were implemented

during the consenting process. I explained any inquiries regarding the research to the woman's satisfaction and subsequently acquired a signature on the informed consent form. All enrolled women received a signed and dated copy of the informed consent for their personal records. Participants also were informed they could withdraw consent at any time, and refuse to answer any question(s) at their discretion. Additionally, the women could opt to not have the interview recorded in which case I would be taking verbatim notes for accuracy. As it turned out, all the participants were comfortable to have the interviews digitally recorded.

Confidentiality

The sensitive nature of femininity, sexuality and breast cancer required that particular attention be given to assurances of anonymity. Approaching an individual for consent could be interpreted as a power imbalance or coercion or intrusion of privacy. Hence, I monitored my body language and tone of voice in all interactions with participants to create a non-threatening environment (Creswell, 2014, p. 98). Pertaining to confidentiality, pseudonyms were given to each participant to protect their identity and all personal health information was de-identified. In addition, the prevailing principles of respect for individuals, and beneficence and justice to protect human subjects were applied to all participants.

Research Methods

Purposive sampling, a non-probability method of conscious selection of research participants (Burns & Grove, 2016, p. 345), was utilized for the study. With purposive sampling the participants were intentionally chosen to reflect a group of the population of women that were able to give detailed descriptions to understand the beliefs, self-perceptions, experiences of breast cancer, sexuality and femininity.

Selection Criteria

Women fulfilled eligibility to participate in the study with self-testimony of (a) a diagnosis of early stage breast cancer (stage 0-3 disease that had not spread beyond the breast and/or axillary lymph nodes), (b) completion of primary breast cancer treatment defined as breast conserving surgery, mastectomy, radiation therapy and/or chemotherapy three months or greater prior to the interview date, (c) a chronological age equal to or greater than 65 years at the time of the interview, and (d) who spoke English. The exclusion criteria were a history of previous malignancy (excluding non-melanoma skin cancers) or stage IV disease that was defined as distant metastasis to other organs such as the liver, lungs, bone or brain. The intent was to include only women who were not dealing with acute effects of treatment from chemotherapy, radiation therapy and surgery. At the start of the study the assumption was that treatment for early stage breast cancer would be in the past while women dealing with advanced stage breast cancer would continue to receive treatments on an ongoing basis for underlying disease. Additionally, we assumed that women with advanced disease might be dealing with mortality, pain management and end of life issues. Thus, to study sexuality and femininity, only women who were diagnosed and completed treatment for early stage breast cancers were invited to participate and were included.

The inclusion criterion of treatment completion from three months and beyond was refined with an IRB-amendment after the first nine interviews were analyzed. At that stage the period after treatment ranged from 53-516 months and it became evident participants who had completed treatment in the remote past were deficient in rich descriptions of the study phenomena. Data analysis demonstrated that women who were further beyond treatment did not have a clear recollection of the breast cancer as their lives had returned to normalcy. On the other hand, women who had completed treatment more recently had a clearer memory of the impact of cancer on the

phenomenon of the study. To ensure a richer portrayal of the study phenomena, the criteria were modified from the open-ended completion of primary breast cancer treatment to 6-36 months prior to the interview date (see Appendix A for range and mean of completion of primary treatment).

Recruitment Procedures

After approval from the South General Institutional Review Board (IRB) at the University of California, Los Angeles, recruitment of the potential participants commenced from multiple Southern California county sites of Los Angeles, Orange, San Bernardino, Ventura, Riverside, Santa Barbara and San Diego. Study flyers that informed potential participants of the details of the study were displayed with permission in public areas such as patient education center areas, waiting rooms, exam rooms, foyers of churches, community centers, tables in courtyards of churches, craft fairs, specialized intimate apparel stores, laundry room announcement boards, retirement communities and community resources where women aged 65 years or above could be expected to frequently spend time (see Appendix B for Study Flyer). Additionally, flyers were distributed to oncology registered nurses attending educational events in Southern California. The potential participants contacted the principal investigator via a study-dedicated cell phone and/or e-mail as the initial point of contact (see Appendix C for Screening Consent Script). The principal investigator's phone number, dedicated to the study, and e-mail address were included on the flyer as a contact for the potential participants. The cell phone message additionally contained a voicemail, which invited potential participants to leave their contact information along with the best time for the return call. Study flyers were also distributed via electronic and hard copy versions at public and private venues. Additionally, potential study participants were invited to participate at holiday and social events such as craft parties, holiday caroling events, monthly holiday celebrations, coffee clubs, breast cancer support group meetings and

written announcements in weekly and monthly newsletters at churches, retirement communities, community based breast cancer educational events such as breast self-exam teaching demonstrations at health fairs and advertisements in newspapers.

Key to enrolling participants for the study was that I spent beneficial time and established a relationship with key contacts at community and cancer support centers, retirement communities, clinics and stores. At these potential recruitment sites, I arranged information sessions regarding the study details, purpose and eligibility. The agenda for these meetings included reviewing study details and purpose, obtaining approval to display flyers, interacting with residents or clients and providing breast cancer educational sessions at the site. The intent was to obtain access to the site and the intended potential participants and establish trust with the faculty, staff and employees of the sites.

At one point during the recruitment phase, accrual of participants was extremely slow, and the IRB approved an amendment to invite eligible participants from a previous study to volunteer for this study (UCLA IRB 15-000431). The Principal Investigator of the previous study (UCLA IRB 13-000526), Dr. Huibrie Pieters, was also the faculty sponsor for the present study. In the previous study participants had signed informed consent that they were willing to be contacted for future studies. Dr. Pieters, who had conducted the interviews in the previous study, called eligible participants to ask if they would be available to receive a call from the doctoral student and participate in another study. Scripts for the recruitment calls from Dr. Pieters and subsequent calls from Melissa Scalia were created and approved for this purpose (see Appendix D for Dr. Huibrie Pieters' Invitation Script). Seven women were invited and all agreed to participate. However, two were not interviewed because, in the case of one woman, she was pleased to acquire gainful full-time employment hence citing insufficient time for the interview. The second woman experienced an unexpected death in her family and

conveyed she was no longer in the frame of mind to discuss sensitive matters. Thus, successful enrollment of women from a previous study resulted in 5 of the 19 participants that were interviewed for this dissertation research.

Snowball sampling was also used for recruitment. That is, after completion of the interview, participants were invited to refer other women to call the researcher. While this peer recruitment stratagem is recommended to access research candidates in hard to reach populations that possess social networks (Burns & Grove, 2016, p. 346), no one responded.

Eligibility screening was completed by phone by the principal investigator with the approved screening script algorithm created exclusively for the study (see Appendix C for Screening Consent Script). After eligibility was confirmed, the potential interview was scheduled for a date, time and place of the participant's choice. To enhance retention of the potential study participant, a polite reminder telephone call was made the day before the interview appointment.

Sample

Of the 31 women who expressed an interest to participate in the study, 22 women were eligible. The reasons nine women did not meet eligibility requirements were the following: completion of treatment out of range (n=4), a history of previous cancer (n=3), and metastatic breast cancer (n=2). Additionally, three participants were screened as eligible but withdrew from the study citing scheduling conflicts (n=2) or a family emergency (n=1). Nineteen participants, all residing in Southern California, completed the study requirements with data collection occurring from August 2015 to January 2018.

Data Collection

Data collection started after approval was received from the Institutional Review Board (IRB) from the University of California, Los Angeles. The setting for the interviews was the participant's preferred site with consideration given for a venue fit to grant

adequate privacy for a conversation about sensitive topics with minimal distraction from ambient noises. Women primarily chose their residence (n=14) or a familiar venue close to home such as a private consultation room at a cancer community support center (n=2), a senior center (n=2) or a café (n=1) (see Appendix E for socio-demographic characteristics including details of settings). Interviews ranged from 43-103 minutes in duration.

After informed consent was obtained, the participants were asked for demographic and clinical treatment information. The principal investigator recorded the answers on the demographic form (see Appendix F for demographic and clinical treatment questionnaire for the complete list of questions).

Interviews

Interviews were conducted in English with a semi-structured interview guide that was especially designed for the study. Accommodations for lighting, use of visual aids, reduction of ambient noises and face to face positioning was utilized to minimize the effects of aging on the sensory system.

The semi-structured interview guide (see Appendix G for interview guide) was based on current research findings about sexuality, femininity and breast cancer along with development guidance of three female community advisory board members composed of women aged 65 years and above with a previous diagnosis of early stage breast cancer. Additionally, the principal investigator utilized her many years working as a nurse practitioner in a gerontology-oncology setting with older women diagnosed with breast cancer. The life stages of girlhood, adolescence and womanhood were intentionally chosen in the development of the semi-structured interview guide. The guide was utilized as a directional mechanism for the interviews. Each interview explored the story and experience of the individual participant. The act of assembling the interview into a life story of the participant enabled a passageway for both the participant

and myself to construct the understanding of the development of sexuality and femininity via engagement of noteworthy life events, perceptions and processes framed in a social context. It was not my intent during the interview to ask a set number of questions or to retrieve a detailed set of answers to a pre-set questionnaire. The quest of the qualitative research and goal of the entire interview was to elicit the life story of the participant's perceptions and experience of breast cancer, sexuality and femininity.

Interviews in the constructivist tradition are a dynamic interaction between the participant and researcher to obtain rich description in the participants' voice to advance understanding of the study phenomena (Charmaz, 2014, p. 91). Mutuality in the development of the research participant's story is a fundamental principle when interviewing in constructivist grounded theory. The key points which distinguished my constructivist grounded theory interviewing technique from ordinary conversation were the use of a dynamic semi-structured interview guide utilizing open-ended and follow-up questions to elicit detailed rich data (Charmaz, 2014, pp. 68-70). As applied to the dissertation, I remained attentive to the conversation direction and did not allow my line of questions to slip into an interrogation of the participant. This was especially important in the study because an interview about sexuality, femininity, intimacy or health-related inquiries with a relative stranger could have been perceived as intrusive. Thus, special attention and sensitivity were maintained throughout the research process and interviews due to the sensitive nature of the questions. I monitored the non-verbal and verbal behavioral cues of the participant and chose questions carefully and asked them slowly to facilitate the participant's self-reflection. During the interview process I listened intently and asked follow-up questions when necessary to validate the meaning, perception and experience conveyed. My overall goal of each interview was to gently guide and encourage the participant to answer questions with in-depth, profound and rich responses. Lastly, my age of more than 50 years may have been an advantage

since participants might have been more willing to speak with someone older and closer to their age regarding sensitive topics.

In all regards, it was paramount that I sustained a professional demeanor and concern for the participant's comfort level as a high priority throughout the interview. Vital to the interviews was the establishment of an environment of trust, acceptance and comfort. To accomplish this task, I opened the interviews with a couple of general questions to allow the participant to introduce herself and the topic of research interest. The next few minutes required assurance that her information was vital and of great interest. Supporting the participant with the reassurance there were no right or wrong answers to questions maintained open communication and an environment of acceptance, appreciation and validation of her viewpoint and experiences. My intent was to emphasize her value as a genuine authority. Sensitive questions were asked during the middle segment of the interview, concluding with less stressful topics (Rubin & Rubin, 2012, pp. 107-113; Charmaz, 2014, pp. 62-68). To wrap up the interview, I asked if there was anything essential to the research that had not been discussed and that she wanted to add.

Digital Recording, Verbatim Transcription, Field Notes and Rigor

Fidelity is a dimension of utmost importance in data collection (Creswell, 2014, p. 99). It was my task to reproduce the data as it was evident and presented in the field during the interviews. Digital recordings of each interview, verbatim transcription by a professional transcriptionist along with the reflective journaling, memoing and field notes enhanced trustworthiness. I reviewed each transcription for accuracy by comparing the transcription against the digital recording. During this check for accuracy, I also de-identified identifiable information. Dr. Huibrie Pieters, dissertation chair, provided continuous consultation with review of digital recordings and transcriptions to verify accuracy, credibility and authenticity. Subsequently, this two-person analytical team

working independently, collaboratively and attentively facilitated the verification of emergent themes, subthemes and perceptions to preserve investigative rigor.

In addition to the digital recordings from the interviews, field notes were an important data source. Field notes were maintained during and immediately following each interview. I recorded field notes including my overall impression of the interview, non-verbal behaviors or cues, emotional responses of the participant and myself, time entering and leaving the field, location, description of the setting and methodological remarks. Details also included her general tone of voice, pace of answers or pauses in conversation and observable body language. It was essential to maintain all field notes and a reflective journal with my thoughts, feelings, perceptions, associations and emerging ideas during this process of data collection, analysis, coding and theme development (Charmaz, 2014, pp. 168-9). Later during the analytic process, the field notes also served to refresh my memory of the conversational direction and dynamics. Thus, the review of the digital recordings of the interviews, field notes and transcriptions facilitated corroboration of developing themes, subthemes and ideas to enhance the rigor of the study.

Gift Cards

As an incentive the first nine participants received a $20.00 gift card for their time and participation. Two years after the initiation of the study the gift card value was increased to $40.00 to reflect the current trend in incentives for research participants. The IRB protocol was amended accordingly.

Data Management

Data management was key to organize the data gathered during the collection and analysis phases of the study. It was imperative to begin the study with a systematic strategy for data organization prior to the accrual of any participants. I created Microsoft Word files for all data collection information, screening guides, demographic information,

consents, interviews, digital recordings, de-identified transcriptions, observations, field notes, reflective journal entries, participants' names, pseudonyms and identification numbers, and demographic information charts. The de-identified transcripts were subsequently up-loaded to the ATLAS.ti (Version 7.5), which served as an efficient data management software tool for the in-vivo and initial coding process (Friese, 2014, pp. 51-56). Utilization of qualitative analysis software was an important component of the data management process especially given the proficiency of the software to organize, arrange and maintain the data for human analysis (Creswell, 2014, pp. 30-32). The analysis team of my dissertation, the chair(s) (initially Dr. Sally Maliski and subsequently Dr. Huibrie Pieters) and myself, had access to the digital recordings and transcriptions. All files were kept on password-protected personal computers. The original hard copies of participants' consents, semi-structured interview guides and field notes were kept in a locked filing cabinet in my home office to which I alone had access.

Data Analysis

Data analysis resulted from a team approach. Fortunately, both my initial dissertation chair, Dr. Sally Maliski, and subsequently, Dr. Huibrie Pieters, had distinguished expertise from the disciplines of both psychology and nursing in gerontology and breast cancer. This fortuitous circumstance was an enhancement to baseline knowledge for an advanced practice nurse practitioner and a novice researcher in gerontologic breast cancer. The advantage of such an expert analysis team was the enrichment of credibility with internal checks on rigor, debriefings and investigator triangulation of concepts to act as a reliability check.

Qualitative Descriptive Design

The qualitative descriptive research design (Sandelowski, 2000; Sandelowski, 2010) gave me the capacity to fully understand the emerging themes and descriptions from each woman's experience regarding sexuality and femininity subsequent to the

diagnosis of breast cancer and treatment. Ever present in my mind during data collection and analysis was the focus to gain knowledge of each woman's experience. Engaging with the women in the interpretation of their actions, beliefs, decisions, colloquialisms and shared phrases was enlightening. Acting as co-interpreters of action, inaction, spoken and unspoken language or behavior, Dr, Pieters and I independently and collaboratively integrated the data into a rich descriptive story of the human experience of the women.

Constructivist Grounded Theory

Following guidelines from constructivist grounded theory methodology (Charmaz, 2014, p. 239), I was obligated to constantly seek pertinent data from participants focusing on the elaboration and refinement of themes. Grounded theory guided me to muse over or grapple with the data during the entire coding and analysis process to forge emergent ideas and thoughts. Throughout the analysis process I recorded theoretical and conceptual thoughts and conceptual insights on emerging descriptions. This dynamic process in constructivist grounded theory enabled me to integrate findings into the research through adaptation of data collection, semi-structured interview guides, coding and analysis as the research data progressed.

Given that I served as the primary instrument of data collection and analysis it was an imperative aspect of constructivist grounded theory that I examine my assumptions and personal biases prior to and during the investigative process through analytical memoing and reflective journaling . As the comparative inductive process continued, I assimilated existing and new data into emerging themes and subthemes. This circular process of refinement enhanced my ability to identify pertinent data in the analysis sequence (Charmaz, 2014, p. 181). This course of interaction between the investigator and participant enhanced the identification of mutually shaping events and

gave rise to incorporation of improved questions for interviews. The synergy of these actions was an explicit part of the analysis structure (Lincoln & Guba, 1985, p. 16).

Constructivist Grounded Theory Coding

Coding in constructivist grounded theory consists of two primary phases of coding (initial and focused coding) followed by analytic coding (Charmaz, 2014, p. 113). For the purposes of this study, the first two codes were used.

***Initial Coding*.** The critical aim of initial coding is a line-by-line portrayal of meaning and action from the participant's life world vantage point, experience and perception (Charmaz, 2014, p. 113). The fundamental concept of initial coding was sticking close to the data, seeing the action by utilizing gerunds on every information segment to open up the data in the initial step of analysis. The intention was to read between the lines to acquire a profound meaning of the phenomenon, distinctly and conscientiously trying not to apply pre-existing codes or themes to data in a one-size-fits-all fashion. Initial coding was an open process to engage spontaneously in the descriptive and reflective analysis process. This stems from an intense self-reflexivity stance and interpretive process tradition, compelling me to move past the data to embrace new ideas or views. The process of initial coding was tedious, energy intense and, at times, overwhelming. Repeatedly, I found myself stepping back from the process to ask, "What is happening here?" Furthermore, I tried to embody the role of the other to envision the participant's worldview. A poignant example occurred during one woman's interview when she shared her initial response to reconstructive surgery as, "It was a murder, nothing feminine." Her comment allowed me to grasp an understanding that surgery meant to restore femininity, could actually destroy it.

Focused Coding. The objective of focused coding was to sort, synthesize and organize the large amount of data. I did not need to necessarily name the preliminary themes, just start the construction. After initial coding of the first few transcriptions, I re-

read the coded transcripts for emergent, frequent and significant codes to form themes. The implementation of this function permitted me to identify and shed light on my assumptions and judgments and then transcend them. Initially I perceived each participant's story as an individual voice; I then began to hear them as a collective choir. Consequently, similarities and differences between participants were noted which I was able to identify after coding the majority of the interviews.

In addition to initial and focused coding, in-vivos exemplify a rich descriptive word or phrase used by research participants that encapsulates a concept succinctly (Charmaz, 2014, pp. 134-35). These particularly valuable quotations created in the participants' own words symbolize a concept so vividly in description and understanding that its inclusion in the analysis is essential (Corbin & Strauss, 2015, pp. 99-100). Inclusion of these transformative codes have the ability to transport and resonate with the reader, providing an "aha" moment such as seeing the breast cancer diagnosis as a "bump in the road".

Memo writing

Memo writing was of utmost significance and influence. Fundamentally, early memos were a written record of analysis used with the primary intent to preserve my thoughts for further reflection on emergent patterns and descriptive analysis (Corbin & Strauss, 2015, p. 198; Polit & Beck, 2016, p. 270). My fear was making the faux pas of any novice researcher; utilizing an expected framework to analyze the data. It was essential for me to look with extreme vigilance at the data utilizing a thematic lens and use memo writing techniques to sharpen my analytical vision. I did not want to merely fracture the data and reorganize it. My task was to hear, analyze and organize the story of each participant. To do so I repeatedly listened to the digital audio recordings and ruminated over the verbatim transcripts. Repetitively immersing myself in the data I constructed an accurate depiction of each woman's story. The pivotal method of memo

writing throughout the research process enabled me to reflect on all aspects of the interview for improvement opportunities and to stay connected and close to the data and participants as ideas, themes and subthemes continued to develop. To enhance description, I needed to be continually alerted to hunches, thoughts or ideas regarding the spoken and unspoken data along with the interplay between the participant and myself. It was a complex process of connecting the relationships of statements, context, observation and even the unspoken performance of the participants. Writing memos of my thoughts either in a written or electronic journal became pivotal in the analytical process of sorting out my reflections and ideas.

Analytical Memos and Reflective Journaling

Analytical memos and reflective journaling are essential and advanced tenets of the constructivist grounded theory process. Writing analytical and reflective memos throughout data collection and analysis pressed me to obtain richer data, innovatively moving beyond the mere surface of social and subjective life to the intriguing complexity of human emotion, thought and action. I was not merely a passive receptacle of data (Charmaz, 2014, p. 34). As I came together with my participant, both of us active agents engaged in the world, I began to see myself as an interactive vessel constantly undergoing construction and reshaping my worldview. Analytical memo writing and reflective journaling captured the assumptions, possible biases, hunches, directions, fears and feelings that impacted my analysis of the data. This occurred throughout the continuous analytic progression. Moreover, the memos directed my further data collection and lens to pursue emerging themes and codes. This method facilitated persistent and synchronized data progression and analysis.

Diagrams and Charts

As a constructivist researcher, I assume participants construct their own world. Situational analysis commonly used in interview-based studies examined elements,

situations and voices relevant to the perceptions of the study participants (Clarke et al., 2015, pp. 16–17). The techniques of situational analysis were used to manually map the complex interrelationships of the identified elements, positions, and voices allowed me to analyze the discourses and relationships of power. My intentional quest was to illuminate the situation and elements from the bottom up, outside in, and/or laterally to question what really matters in the shaping of perception (Clarke et al., 2015, pp. 20-22). I photocopied my hand-drawn situational map with 50 elements identified in the data and drew lines between the elements. Next, I dictated the nature of the relationship between each element into my iPhone. Subsequently, I utilized Dragon Dictation software to turn my dictation into text for memos and further analysis. The situational analysis exercises throughout the data collection and analysis processes pushed me to recognize new angles to examine the data and shattered some unforeseen assumptions of mine such as how a woman's breasts are viewed after childbearing.

Study Rigor

Study rigor was maintained throughout the research process with stern devotion to the scientific standards of data collection and analysis.

Credibility Strategies

Credibility dictates and signifies that the study findings reflect a veracious account of the participant's experience of the phenomena (Corbin & Strauss, 2015, p. 346). In the case of the proposal, the analysis team, i.e. the doctoral candidate and dissertation chair, maintained the credibility of findings throughout the research process through extended engagement with the collection and analysis of the data. Notably, I immersed myself in clinical, social and educational activities with women aged 65 years or older subsequent to a diagnosis of breast cancer by giving presentations on life after breast cancer and attending social events at community venues to gain a deeper understanding about the social context and views of these women.

Neutrality of questions, another component of credibility, was inherent in the study design during the development of the semi-structured interview guide and conduction of interviews that allowed for agility and synergy vital to the pursuit of emergent themes. This action increased the likelihood of eliciting truthful and accurate depictions of the participant's experience while establishing a non-judgmental rapport with her. Trustworthiness of the descriptive analysis and dependability was confirmed with the use of reflective journaling, analytic triangulation, cross checking of data and interpretation during collaborative analysis and debriefing sessions with my chair.

Elements that ensured transferability included purposive sampling, the capture and reporting of detailed demographic, clinical characteristics and professional transcription of interviews with rigorous detail to the accuracy of content. Transparency of study elements is a historical cornerstone of validity in qualitative research inquiry (Denzin & Lincoln, 2018, pp. 9-12). Inherent in qualitative inquiry is the attentiveness to the thick, rich descriptive elements of the study and the context in which women's lives were experienced in order to enhance further work, application and transferability of the research findings to clinical practice, other settings and populations.

Verification is the key element of confirmability (Creswell, 2014, pp. 201-203). As aforementioned, confirmability was enhanced with the audit trail of the digital recordings of interviews, verbatim transcriptions, writing of field notes, reflexive and theoretical journaling and code checking with my dissertation chair. Journaling of the emergent themes, assumptions, biases and developing thoughts also served as an audit tool for the analysis team.

Another criterion of rigor is the usefulness of the analysis to existing knowledge (Charmaz, 2014, p. 338). As described in the chapters of Results and Discussion, the scholarly contributions of this novel study highlight the complexities of sexuality and femininity in women 65 years or older subsequent to the diagnosis and treatment of

early stage breast cancer. The dissemination of this insightful knowledge will enhance clinical expertise and practice.

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Chapter 5: Results

As the participants were asked to reflect on the impact of the diagnosis and treatment of early stage breast cancer on sexuality and femininity, they naturally voiced in-depth memories. This chapter presents three overarching themes in rich descriptive language to illuminate our findings: receiving the diagnosis and the unique dimensions and appraisals of both experiencing sexuality and describing femininity. Across these three themes, inner processes emerged within the ethereal domain of the women's minds, which triggered an inner evaluation of established dimensions. Another subtheme was outer processes that encompassed the physical dimension of interactions with others and further developed the participants' perceptions. The third subtheme, moving forward beyond the breast cancer experience, entailed the renegotiation of what the participants described as "normal" between the ethereal and physical dimensions. (For the purposes of this paper, normal will be referred to as normality in this chapter.) These results were naturally situated within the context of being an older woman and aging (see Appendix H for an outline of themes and subthemes).

Receiving the Diagnosis of Breast Cancer

Receiving the diagnosis of breast cancer commonly started inner processes that were a jumble of thoughts. These thoughts did not follow a pattern but were random in nature. Themes of shock, fears of disfigurement and other consequences, and also of suffering and gratitude were clearly evidenced in the data. Participants reached out to others, which enabled them to move forward in order to establish normalcy and thrive.

Inner Processes

Shock

Shock was the initial emotional reaction upon hearing the breast cancer diagnosis. The intensity of the shock overwhelmed some participants who described

themselves as being in a haze and unable to process the information given by the clinician. One woman's poignant reflection exemplified this common theme when she recalled, "The minute I heard, my stomach dropped, and I was in total shock." This shock when the disease befell the women happened despite a series of increasingly concerning mammogram results that, for some participants, foreshadowed the diagnosis and the realization anyone could be diagnosed with cancer because these older women were familiar with other breast cancer survivors. A negative family history, advanced age and the maintenance of a healthy lifestyle had convinced several participants that they held a low risk of breast cancer, which amplified the intensity of the shock.

Violent imagery and disfigurement

Violent imagery shaped and defined some women's poignant views of breast cancer and its treatments. Fear of disfigurement contributed to the emotional rollercoaster of terror as a few participants' tumultuous thoughts were muddled with fears of being "hacked up...ruined for life." The prospect of having a breast, the identifying characteristic of the female physique, "hacked off" horrified one of the women. Another participant who said as she strongly exhaled, "Well, I just didn't want my boobs to look like (scoffing) they were all scarred." She added that she was terrified because, "Let's face it, our breasts are what identify us as women…being a woman and feeling good about being a woman, is that we have breasts and men don't." These participants recalled moments of dread, "It was a short period of abject terror and it went away (laughs)." Others feared the interjection of irrevocable change into their lives. One participant succinctly expressed the transformation as, "I was concerned about the fact that I was a living time bomb."

Fear of consequences

The fear of unknown consequences was perceived as a frightening experience with the potential for devastation. Negative impressions were frequently portrayed as, "It

was the fear, you know; cancer is just scary." Powerful and swift, the word cancer generated thoughts of death, mortality and dying for the participants. For women of this sample, the breast cancer diagnosis was the first encounter with their mortality as expressed by one participant with no history of chronic illness who said, "I've got breast cancer, and I'm thinking: Oh m-my God. You know? It's the end of my life."

Cancer history of a family member added to the forecasting of affliction. Many had observed the deconstructive "toll" on others' femininity and dignity across generations. One participant emotionally declared that she would not have chemotherapy after the observations of multiple family members', including aunts, her father and husband, misfortunes with chemotherapy for malignancies. She shared,

> There was no dignity in the end for him (father)…he had pancreatic (cancer)…there was no dignity left there. I want to be able to die with dignity. My dad said to me, too, which just broke my heart, "They shoot horses, don't they little girl?"

Suffering and gratitude

Evident in the data was the acknowledgment of suffering related to resentment, suppression of anger and non-disclosure of the breast cancer diagnosis to others. In striking contrast, the women concurrently expressed gratitude for the detection of cancer at an early stage and older age.

Resentment about breast cancer was clearly evidenced by one participant who said, "Well that's unfair. Why give us these extra things to feed children, and then, suddenly, it's so susceptible to disease or cancer?" Suppression of anger was a common theme as exemplified by the woman who reflected toward the end of her primary cancer treatment, "It kind of makes you angry, even though you suppress it…it definitely is not easy." Some participants carried this burden in silence, which was motivated by the desire to put others before self.

Gratitude for the good fortune of catching the cancer at an early stage and the desirable outcome of not needing a mastectomy or chemotherapy was repeatedly articulated. In the context of one's life span, the age factor for many of these older women generated thoughts on the purpose of breasts and questions on the utility of breasts since completion of the childbearing phase. In response to a question of purpose, one woman's affirmation especially evidenced this when she said, "What for? I'm old. I don't need it. Breast is for breastfeeding, not for anything else… even if it's for something else, my husband is not here." Additionally, some women questioned the wisdom of God to give every woman an organ that provides life-sustaining nutrition for infants yet made breasts so susceptible to cancer. Several saw the diagnosis as more devastating to younger women of childbearing age due to the perceived utility of breasts for feeding and nurturing children and sexual pleasure.

Outer Processes

Upon reception of the diagnosis, many participants reached out to others for assistance. Frequent descriptions included the selective disclosure of information, seeking support from others and the impact of suffering on others. Additional subthemes evident in the data were seeking knowledge and speaking up for oneself.

Disclosure

The impact of the breast cancer diagnosis was both emotionally and physically difficult for many women to share with a spouse, family member or friend. Concerns in regards to the timing, amount of information, to whom, by whom, and where the diagnosis disclosure may occur weighed heavily on many of the women's minds when they received the bad news of a cancer diagnosis. The decisions about these aspects of disclosure added an extra dimension to simply getting through the diagnosis and treatment processes. Frequently the announcement of the diagnosis was withheld or delayed to spare others from worry, pain and suffering. Reasons for delaying disclosure

of the diagnosis to a seemingly more appropriate time and place included a life event or accomplishments in daughters' lives such as pregnancy and promotion. One woman shared how she and her husband were prepared to tell their daughter about the diagnosis, but then she decided that she did not want to steal the spotlight from her daughter's surprise pregnancy announcement of the first grandchild over a family meal, "When she announced it (the pregnancy)…people were so happy for her…I didn't want to bring down - that whole feeling…the grandmother-to-be has breast cancer."

Keeping the cancer diagnosis a secret from co-workers or family members was also deemed necessary in order to not burden others or have them talk about her. Anticipating that others' thoughts after a disclosure may escalate, a participant described what they may think and what she wanted to avoid, "'She's die (dying), going to die soon.' I didn't want to have these people talking about me." However, this participant also acknowledged that others knew about her breast cancer diagnosis despite her personally not sharing or disclosing, "They found out before I told them anyway (laughing) it's a small world...at least I thought they didn't know."

However, non-disclosure was sometimes deemed non-viable. Another participant exemplified the discordance of her inability to share and how non-disclosure did not work out. She pondered if her attempts to "disappear" for six months while undergoing surgery, chemotherapy and radiation therapy were futile because the external evidence of hair loss could not have stayed hidden from the world. The connection between her internal decision-making processes with the outer physical evidence of treatment was exemplified in her statement as, "I decided, "Well, shoot!' You know, my first thought was, 'I just won't tell people (about the breast cancer diagnosis) but I said, that's not going to work (as an option).'"

In the dating arena, being up front and honest with potential significant others was described as a prerequisite. For a participant who had recently started online dating,

the non-disclosure of a breast cancer history was seen as “not fair” in the context of moving dating to the next level of a monogamous relationship. Another participant, who was diagnosed after she started dating, demonstrated this expectation when she revealed to her companion, “Look I got to tell you something. Got to be up front with you. I just got diagnosed with breast cancer.” Thus, not fully revealing the news felt disingenuous to the establishment of intimacy with another.

Disclosure of information for one participant involved delegating the task to a close female friend to share the news. However, such secondary disclosure of the diagnosis was unsettling for others to hear as the recipients felt unsure if they should have this knowledge or if the woman desired the news being shared at all. This was particularly exemplified when the participant requested a close friend to share the diagnosis news with the intimate circle of female friends at her church, and the group of women reportedly said, “Are you sure she wants us to know (gasp), are you sure?”

Support from others

Participants’ perceptions of positive support alleviated the impact of the negative experiences of receiving the breast cancer diagnosis and treatment, whereas the perceived lack of support was identified as a source of feeling bereft. Common descriptions included, “I expected him (husband) to like be more embracing (looks off in the distance, tearful)…it’s been tough.” Strong support was greatly valued and appreciated especially when receiving chemotherapy, a mastectomy or both as evidenced after one participant’s unilateral mastectomy. She remembered, “Even when I took off the bandages, I said I don’t want to look…I don’t wanna look. He (husband) was, ‘No, no. Okay, now let’s do it slowly’…he supported all through that.” In addition to emotional support, reliance on a family member for the acquisition of information about treatment decision-making was an essential part of the ability to move medical care forward.

Suffering of self and others

Informing others and sharing treatment-related experiences were associated with perceptions of distress and suffering in spouses, family members or friends. One woman and her significant other who possessed a strong emotional and spiritual bond, both experienced anxiety and weight loss. At times the burden required a shift in focus of the sick role from self to the significant other. Poignantly one woman shared her story about caring for her significant other's emotional needs and how it took precedence over her own chemotherapy appointment,

> He suffered so much…he got so anxious…I had to take him to the E.R. (emergency room) and leave him there (laughs nervously) while I went to chemo…he thought he was going to die from an anxiety attack…it's not a heart attack…okay I got to go for my chemo.

Tenaciously this woman balanced the care and role of the sick partner between herself and husband.

Across participants the married women compared themselves to their husbands regarding the level of distress that were experienced with the cancer diagnosis. Commonly they perceived that their spouses were more distraught, "I didn't really worry too much about it…I think my husband was more worried than I was." These perceptions of dependency of family members amplified the impact of the diagnosis of breast cancer. The inability to take on the sick role due to caregiver responsibilities was prevalent. Women foresaw a negative impact of treatment side effects or mortality on significant others given their reliance on participants for everyday activities such as food preparation, medication administration and hygiene maintenance. As described by a woman who reflected on why an anticipated decision would be particularly hard for her when she said,

> He needs somebody to look after him…I was a little worried that they (MD) would say okay, now we're going to do the mastectomy…I knew I wouldn't be able to do a lot after…that was the hardest part.

Fortunately, a mastectomy was not recommended for this participant.

Seeking knowledge

The pursuit and acquisition of knowledge was a common mechanism to manage anxiety and fear in regards to the cancer diagnosis and subsequent treatments. There was an acknowledgment that the acquisition of information assisted in learning to relax, as evidenced by a woman who remembered, "I went to seminars and classes…it was a little help." For another woman the maintenance and retention of a "cancer box" of information and knowledge symbolized the relegation of cancer to its place.

Speaking up

Assertively speaking up for oneself resulted in receiving the necessary care in a timely manner. One participant who assertively voiced her needs about the timing for an essential surgical treatment said,

> I did complain, 'cause my doctor wasn't going to do the surgery right away because he was going on vacation…I called and said "Could I have another surgeon?" I (laughs) don't want to wait…so he did (laughs) I got it done (laughs).

Once she advocated for herself, the procedure was done before the surgeon went on vacation. Other women recalled being insistent about the need to convince physicians of the necessity to perform additional diagnostic tests despite negative mammogram results to validate their suspicions of breast cancer. One woman concluded, "I can tell the girls (friends), 'if you find something, don't wait, that the doctor said 'Come back in six months.' You demand to have a biopsy right there. You don't wait." Due to the perceived lack of information and education available about breast cancer and mammograms, the women viewed themselves as a valuable inspiration and an

educational tool for others. These were poignant examples of women standing up for self and others.

Moving Forward

Moving forward toward the restoration of normality was evidenced in personally understanding the reality that cancer commonly happens and the awareness that the participants found their thoughts transition from death back to life. The face-to-face encounter with cancer and coming to terms with one's mortality was an imperative element of the inner processes to move forward past the diagnosis and place the cancer experience in perspective.

Cancer happens

The common realization that anyone can get cancer aided the acceptance of receiving the bad news. In one narrative the participant echoed how breast cancer was also a good experience as she associated it with a time of self-reflection and quiet, *"*Relatively a good experience…spiritually and emotionally…in spite of being cancer*."* Additionally, she remarked on the purpose and need of the diagnosis to get her life in order as, *"*God might be knocking you on the head...Wake up. You need to pay attention to this …your body…what you are doing*."* Alternatively, another woman reflected back on her experience of receiving a breast cancer diagnosis and treatment as neither a good encounter nor a learning experience, "I would never say it was a good experience. You know some people say 'Oh you know I learned so much dah dah dah'…I would never want to go through it again*."* Another participant stated that she had done all the right things yet ended up with breast cancer that she referred to as, "creepy cancer."

Moving from thoughts of death back to thinking about life

Society was often perceived to equate breast cancer diagnosis with a death sentence, as illustrated by the woman who said, "A lot of people think it's a death knell*."* Initially frightened of death, many participants proceeded to accept the diagnosis as part

of life's aging process. The transformative nature of a cancer diagnosis was exemplified by one woman's life expectancy outlook when her perception altered from being the healthy spouse to the one with a life-threatening illness. This disequilibrium led to a reversal of the couple's earlier premises of who would die first and the re-evaluation of their financial planning strategies that were in place at the time. Her thought process was expressed as,

> Our financial decisions…the way we conducted our lives was kind of based on that premise (husband dying before wife). All of a sudden, I was thinking, "Uh oh, I might die...it's a very life changing event…you have to readjust your thinking about your life.

Several women saw the breast cancer diagnosis as a life changing event, turning their life expectations upside down or 180 degrees from previous beliefs. However, while a readjustment took place in view of life expectancy, the cancer experience did not alter the woman's priorities of life subsequent to the breast cancer diagnosis. The disruptive element of the diagnosis rearranged plans of retirement, travel and finding love, thereby putting some of life's plans on hold. In one poignant illustration a woman articulated the financial capacity, emotional fortitude and resilience to move on with romance and retirement subsequent to the death of her beloved spouse only to abruptly receive her breast cancer diagnosis. Her thoughts of death and mortality turned to the importance of a dynamic existence and abundant life with cherished loved ones as she reflected, "It was about life."

Moving past the diagnosis

Moving past the breast cancer diagnosis was often accomplished when participants took the next steps after the initial emotions of shock, disbelief and terror had diminished. The diagnostic procedures and various treatments permitted the women to view the cancer as being taken care of quickly, to be over and done. Having lived for

65 years or more these participants had an ability to view breast cancer within the context of their entire lives. Repeatedly, women described the encounter with breast cancer as a small fraction of time in the entirety of their life span, as “a bump in the road.” Initially feeling shock along with jumbled thoughts, the women were eventually able to look at the breast cancer diagnosis as an element of their personal history. There was an element of comfort in knowing the appropriate next steps or actions to take along with the sense of just getting through the breast cancer diagnosis and treatment. Looking straight ahead and focusing on what needed to be done, participants frequently verbalized their belief that the cancer would all be taken care of by the prescribed diagnostic and treatment modalities. This positive anticipation was expressed by a participant who remembered that the diagnosis did not concern her as she placed all her attention on treatment. She said, *“*I knew what the steps were…it (breast cancer) didn’t bother me.*”* Thus, trusting and believing that health care professionals knew the right course of action to successfully treat the breast cancer and adherence with the physician’s recommendations of treatment enabled the women to move forward.

Putting breast cancer in its place

Placing their breast cancer diagnosis in the context of growing older, a few participants noted that many peers in their age group and social circles had received the same diagnosis. A perception of normality and commonality existed for these participants in the interface between aging and receiving a diagnosis of breast cancer as the cancer was then seen merely as part of growing older. This commonality was described by a woman who reflected on friends her age when she stated, “So many people have breast cancer that it sort of goes with the territory.” Breast cancer was then seen merely as part of growing older. The perception of breast cancer as part of the aging process positively influenced the participants’ thought processes, interactions with others and the ability to re-establish normality of life. The commonly expressed attitude

of the older women of this sample was to purposefully move forward. Evidence of an attitude to progress with life was reflected in one woman's statement as,

> Get over it (breast cancer)…you can't live and say 'Oh, I had breast cancer,' and feel sorry for yourself…I was pregnant. I had a baby. It's over with (laughs). I had breast cancer. The cancer's gone. It's over with (laughs).

Although most of the women viewed any dealings or encounters with breast cancer as something in the past, some individuals maintained persistent thoughts of cancer. Despite the reception of a favorable prognosis, some participants retained intrusive thoughts of possible recurrence. Frequently evidenced among these women was the acknowledgment that their body's ability to make cancer meant the disease could happen again. The unshakable realization and enduring possibility of cancer's return was shared when one participant said, "So it starts there and you never stop after that." One woman felt that she did not get the full picture at the time of the diagnosis. Later she grappled with the restoration of normality while living with the possibility of cancer's return.

Experiencing Sexuality

Across the sample women were initially unsure how to approach questions such as, "What does sexuality mean to you?" and "How would you define sexuality?" Although the participants were highly educated and responded enthusiastically and verbally on other questions there was evidence of ineptitude, a loss for words and lack of experience to converse about sexuality. One participant exemplified the inadequacy to find the words to describe sexuality when she said, "Well sexuality, I don't, I'm not sure." Awkwardness in the ability to express sexuality occurred despite the fact that throughout the pre-interview process, the women had the opportunity to ponder the notion of sexuality and breast cancer because both words were on the recruitment flyer, and they also had awareness of the intent of the study via the phone-screening interview. Despite

the time period to think about the purpose of the study between the screening interview (when sexuality was clearly stated), and the interview, describing their understanding of sexuality posed a challenge.

Many participants had not discussed sexuality openly with family or friends, so they had not thought much about the description prior to the interview. The scarcity of open social dialogue regarding sexuality was dismissively reflected by a woman who said, “We don’t sit around and have intimate conversations about sexuality (scoffing)…I-I don’t know. I don’t know what to say about that.” However, as each interview progressed the essence of sexuality was perceived and articulated as an innate element of self.

Descriptions of sexuality after breast cancer were mostly situated in sexuality before the disease. The first of the three subthemes about sexuality was a comprehensive dimension of inner and personal processes that was shaped through sexual education by mothers, family members, teachers, friends and society throughout the women’s life span. Another subtheme included outer processes where participants described the diversity of sexuality by sharing their lived experiences in reaching out to others. In the final subtheme, moving forward past breast cancer, the women demonstrated their resilience and ability to adapt their sexuality to life changes and strive to flourish.

Inner Processes

Inner processes unified the acquired sexual knowledge with navigation of unspoken taboos and societal values into a framework for sexual experiences. For the participants the scarcity of sexual education received during their earlier years of life heightened the position of feeling naïve, awkward and uncertain about engagement in sex, reproduction and sexual intimacy.

Proceeding with limited education and naiveté

Mothers, family members, teachers and friends acted as the primary repository of sexual information and education for the participants. Quite a few mothers reportedly supplied a book on menstruation and sexual education, yet did not discuss the book's contents with daughters. Another source of sexual education was via moral science classes in Catholic schools. The content that participants remembered from these interactions was limited to topics such as where babies came from and the biological mechanics or concrete facts of sex, but they described that their learning lacked the emotional dimension. Contemplating sex education training received while attending an all-girls' Catholic boarding school during her adolescent years one participant said, "We had a moral science class…little stories of right and wrong."

Naiveté regarding sexuality was commonly reported among the women of our sample. Several spontaneously identified themselves as naïve regarding sexuality, reproduction and sex. One woman's humorous account described how as a child she avoided allowing anyone, even immediate family members, to kiss her out of fear of pregnancy. She said, "I thought that you got pregnant by kissing and I would not let anyone kiss me, ever, even my family and my relatives (laughter)*."* Another woman reminisced about the lack of knowledge and experience in the statement of, *"*As far as a sexual relationship with another sex, no, I, I was naïve."

Navigating around the taboos

The mostly unspoken code of sexual conduct and the sexual taboos of dating were common reminiscences. By not speaking with their mothers about sexual matters while dating, many participants learned by trial and error. This approach led to a lack of self-assurance, feeling hesitant and afraid of sexual contact, as recounted by the woman who said, "When I first started going into my sexual phase I was very timid and intimidated…I didn't have the confidence because my mom always said it was a dirty

thing." The women received mostly negative sexual education about what to avoid as opposed to positive guidance from their mothers. A few participants recalled their mothers making sex seem dirty in an effort to deter sexual activity and the stigma of premarital pregnancy. To avoid being considered "a slut", one woman recalled, "It was pretty much known in our family that you better not have sex before you are married." In the case of two participants, open yet limited dialogue about sex only occurred the night before the woman's wedding.

Societal values

Societal values at the time of the women's youth did not allow for open discussion of sexual activity in either private or social circles, as exemplified by a participant who said, "People were not forthcoming with information like this. Everything was hush-hush." Avoidance of premarital sexual activity was a societal value and an expectation that was clearly described by all the participants. On the contrary, no consequences were seen for men's participation in premarital sexual activity. If an unwanted pregnancy resulted, men were described as having the choice to be responsible, stated by a participant as "let's get married", or refuse to take responsibility that was summarized as, "That's your problem". Conversely, for the women, the potential cost of coitus was pregnancy which included the inability to hide one's sexual activity, "everyone knows in your small town" and the necessity of dropping out of school. Birth control, specifically oral contraception, was not an option for some women either due to accessibility or the stigma of prescription usage due to religious dogma and social doctrine. One participant described this inaccessibility of pregnancy prevention choices as, "This was before birth control (oral contraception)."

Giving limited education

Although the women realized the lack of open communication regarding sexuality was not an optimal method of dissemination of knowledge and that they experienced a

lack of confidence, several participants perpetuated the convention with their own daughters. Reflecting back on her role of providing sexual education to her daughter, a participant recalled not spending much time discussing sex specifically, “I don’t think I really spent a lot of time with her on talking about that (sex).” She equated being straightforward with the use of correct body terms and acquiring birth control pills as sufficient for her daughter in lieu of a discussion of the facts of life. The same participant deferred inquiries from her granddaughter to “you better ask your mother.” This participant saw herself as being “old school” by letting the mother explain sexuality to her grandchild since it was the responsibility and authority of the parent in regard to what, when and how information was shared.

Outer Processes

In an effort to experience the various dimensions of their sexuality, participants reached out to others in learning by doing with an appreciation of these intimate connections. The essence of this multidimensionality was eloquently encapsulated by one participant when she said, **“**It (sexuality) isn’t just having sex. It’s, it’s a whole being, being… Well, it’s your being…there’s a lot that contributes to it, your ideas, your body, your welfare, they’re all-it’s all-an all-around kind of thing.” Sexuality for these older women encompassed a wide spectrum of current lived experiences of sexual desire, intercourse and intimacy from “none” to a yearning for preservation of the facets of sensuality. Although their phase of life played a distinct role in the purpose of sexual intimacy or intercourse, the majority of these older women spoke with high regard about the act of sexual intimacy.

Learning by doing

Learning by doing was evidenced as an outer process as multiple women described that “back in the day” was a reflection on the lack of open discussion of sex. The reliance on guidance from a more knowledgeable husband or sexual partner

assisted in the acquisition of the physical mechanics of sexual activity. The women recognized their knowledge deficit due to societal customs and that their sexual education solely occurred through the engagement in exploration of sexual activity. A woman who addressed this learning by doing said, “Back in the day we really did that. So, I guess I just learned hit and miss, like hugging and kissing and then progressing on my own.” Congruent with the lack of guidance or education from family or community resources, women recalled being frequently apologetic to their sexual partners in regards to sexual inadequacies, their lack of knowledge and experience.

Multidimensional facets

Although the women were unsure how to respond to the initial question that invited conversation about their understanding of sexuality, their responses later in the interview regarding sexual health typically led to richer descriptions. Sexuality was described as multidimensional and comprised more than just desire, the ability and act of sex. Dimensions of sexuality integrated a physical and spiritual connection with another human being created by a higher power for the mutual benefits to the body and soul. Intercourse was continually distinguished by the women as the ultimate act of intimacy and expression of sexuality. Sexual health was embedded in sexuality and described as an essential component of life, a vitality that encompassed the physical, emotional and spiritual capacity to desire, engage in and enjoy sexual activity. Women espoused the importance of intimacy, spirituality and the contribution on positive sexual health outcomes, as exemplified by a participant who said,

> Sexual health—sexuality, if it’s not practiced with all the dimensions of its responsibility, of its potential spirituality, its responsibility for health, for spirituality, for wisdom, without that it’s, it’s almost violent. It’s a betrayal of the whole story.

For many participants the act of coitus was reserved exclusively in committed monogamous relationships such as marriage. This was in opposition to one-night stands or “friends with benefits” sexual encounters which were scrutinized as empty, meaningless and devoid of the essential spiritual and emotional dimensions. An uncommitted sexual encounter, as one woman asserted, “turns sex into another athletic event…it loses the spirituality…it’s sex as entertainment.” A few participants saw the endangerment of sexual health, sexuality and intimacy due to current societal promiscuity practices, sexually transmitted diseases and the devaluation of sexual intimacy. The preservation of personal morals and values were described as an essential component to sustain the integrity and significance of sexual encounters, specifically sexual intercourse.

The vital elements of sexual intimacy were defined as a bond created by open communication, the selfless desire to satisfy someone else and the ability to construct a spiritual connection, as demonstrated in the reflection of a participant who said,

> Just wanting to satisfy that person and make them happy, too (pause), the closeness…snuggling and talking…being together…a lot of times is more better (laughs) than the sex part…that connection you have, to me, that spiritual thing is very important. I can’t do sex without the spiritual thing.

The dimension of emotional health was illustrated by being open and receptive to sex and sexuality as described by the woman who said, “Just be close to each other and feel each other’s body heat…just the love, you know, you just feel the love. A good, healthy, fulfilling thing.” Desire for sex and the pleasure of orgasms were essential components to be preserved. There was also a commitment to maintain personal hygiene and to remain free of sexual diseases. To ensure the continuation and preservation of sexual vitality several participants advocated annual health exams to guarantee the body was functioning properly.

Coitus - sexual intercourse

The strong association with the sex act, intercourse or coitus came to the women's minds when they responded to follow-up, open-ended questions regarding sexuality. Overwhelmingly, all the women recalled sex as delightful when they were younger. Gleefully expressed by one participant in her narrative on sex as, "A lot of fun when you're young (smiling and laughing)." Several women expressed the strong linkage of sexuality to procreation in younger women alongside with the exclusive purpose of coitus for reproduction in marriage. In a concrete illustration a participant teased out that the function of sexual intercourse for younger women is procreation and for older women is pleasure. She said, "Cause I think that's what sex is. It's intercourse for a baby and when you're younger, and for pleasure when you're older.*"* The participants spoke about the modification of the intent of sexuality and sex in women of their age for enjoyment. Purposefully making a "sex date" helped one woman forge out the memory of the enjoyment of sex at times. The participant shared the results of a planned night of sexual intercourse with her spouse as, "Wow that was nice, I forgot." In addition, a number of women cited not having sexual relations with husbands but feeling content and happy with their relationships despite lack of physical contact or intimacy.

Diversity of lived experiences

The diversity of expressed sexuality in regards to engagement in intimacy and activities related to sexual intercourse of some participants included attitudes of why bother with being sexually attractive when your significant other cannot respond to your sexual desires or needs. Several women reported that their husbands' history of prostate cancer, declining cognitive function, dementia and progressive disease resulted in the loss of physical intimacy. These participants exemplified an ability to sublimate their libidos and sexual needs to accommodate their husbands' limitations as a woman described in one poignant narrative,

> When (husband's name) had the prostate cancer, my desire went straight down, too. So, I don't feel like I miss that anymore in my life really. I have really no libido. Even if I see something like on the movies, doesn't do anything for me, you know (laughs). When you're a kid it kind of just makes you feel like hot and bothered…I could just tell you that he hasn't touched me since I had the surgery (unilateral mastectomy)…mostly just sadness (looking down tearfully).

Other women acknowledged having no current sexual partner since the death of their spouses or lack of a suitable romantic partner due to advanced age. For these participants, sexual intimacy currently was non-existent as exemplified by a participant whose spouse had died many years ago. She said, "There is none (sexual intimacy)."

The women of the sample spontaneously acknowledged societal preconceptions of older women's diminished sexuality. Yet, the participants affirmed their experience and motivation to retain this essential part of self, as vividly expressed by one woman, "I don't think a woman should ever lose her sexuality… I'm hoping I never lose it because that's part of me." For this woman, demonstrating her sexuality included imitating a model strutting down a catwalk when out in public to exemplify her idealized version of sexuality,

> I try to put the little swing in my walk but I don't go to a point where I try to get noticed with it…I try to walk like, you know, like the girls on the walkway…that's how I maintain (sexuality)...right, that's how I maintain.

In contrast her private version was being herself and letting her stomach hang out. Additionally, this same participant addressed societal assumptions about the sexual activity of older women when she stated, "Sexual wise…I consider myself as being 70 and still having, wanting to be with someone, you know."

The existence of a limited remaining time period that an aging individual can physically participate in sexual activity, specifically sexual intercourse, weighed heavily

on several participants' minds. The women expressed earnest statements and questions regarding realistic expectations of sexual activity within the context of growing older. Illuminated in the reflection of one participant as, "How much longer are you really going to be able to have an active sex life? I mean I don't know, when you're 80 – people have sex when they're 80?" The women in the sample had firsthand knowledge of the impact on sexuality of age-related infirmities such as cancer, Alzheimer's disease, diabetes, heart failure, and erectile dysfunction. In the case of one woman there was a perceived "actuarial clock ticking" defining the limited time available in her life and consequences of aging to find love, enjoy intimacy and be sexually active within a committed relationship. For this one participant the pursuit of an intimate relationship resulted in a feeling of urgency in the task to restore intimacy and sexuality after being treated for breast cancer.

Moving Forward

After the shock of receiving the diagnosis wore off, life continued for the women with the re-establishment of sexuality through the acknowledgment and transcendence of barriers to sexual intimacy. Both the women who were married or in a committed relationship and the participants who were not described the modified aspects of intimacy after the diagnosis of breast cancer. Despite the changes in sexual intimacy the women described their fulfillment in the role of older wise woman.

Physical changes

Women were cognizant of changes in the body due to cancer treatment and advancing age along with the struggle to maintain intimacy with self and others. In the case of four participants the loss of sensation after breast surgery lingered and created avoidance of looking at and touching herself along with a loss of libido and disruption of passion. One woman poignantly reflected on the loss of breast sensation on the pleasure of sexual arousal from foreplay after her mastectomy when she shared, "The

stimulation you know because the breast was gone...that was something that I really enjoyed and missed…the nerve endings are gone…capacity was gone, physically gone…it interrupted the passion." Two of the women spoke of their aversion to look at the affected breast or touch themselves after showering. A participant who underwent a lumpectomy 12 months prior said, "Taking my showers and I'd have to put my cream on afterward (chuckles) and I'm like, oh, God, (laughs) I don't want to look there. It just made me feel, I don't know, kinda deformed."

Anti-hormonal treatment

A large percentage (n=18; 94.7%) of the women of this sample took anti-hormonal treatment for estrogen-positive breast cancer after the primary treatments were completed, which accentuated or re-initiated the menopausal experience of hot flashes, vaginal atrophy and dryness. One common consequential concern that nine participants spontaneously voiced was the symptoms' disruption of the natural relationship of sexual desire, activity and intercourse. Additionally, the women acknowledged their trepidation in regards to initiating a successful sexual relationship with men in their age group. The participants' perceptions were that age-matched men were likely to have a sexual performance concern such as erectile dysfunction. One woman eloquently articulated the significance of menopausal symptoms and aging in maintenance of healthy sexual activity when she said,

> This is the worst part of this. You know, the cancer surgery was nothing. I already went through menopause once, 20 years ago. Now, I have to go through it again...vaginal atrophy is the result of menopause, and I'm just praying that doesn't happen, because I want to have a normal relationship. The other thing, for someone in my age group, it's most likely that men are going to have a problem. It's not going to be the same as it was when you were 20. Okay? But, it's going to be something.

Intimate encounters

A few women currently not in a sexual relationship were open to the idea or prospect of having a romantic partner in the future yet hesitant when looking forward to the possibility of an intimate encounter. Common in the data was the entanglement of desire for physical intimacy with the potential for rejection at the disclosure of the diagnosis. One woman vividly portrayed this dilemma when she said,

> If I should have a best buddy and we thought we might be sexually involved, that would be a real challenge to tell him and to reveal myself physically…that's one reason why I wouldn't, wouldn't risk it. Rejection or short of rejection, turn off."

Additionally, the same woman recalled a movie in which the leading actress received a basket of worms from her love interest after the disclosure of her double mastectomy as a sign of rejection from him. The imagery was powerful and moving, cementing a connection of breast cancer with potential rejection and loss of intimacy for the participant.

Re-establishment of intimate sexual encounters and activity was complicated for four of the eight married women with thoughts of fear that their husbands would see them as less than whole and undesirable. The overwhelming fear of an anticipated lack of libido and mechanical failure of her prosthetic breast device added to the skeptical re-initiation of physically intimate sexual contact for one participant with her husband after the breast cancer treatment and re-construction. She poignantly expressed her initial apprehension based on misinformation as,

> The first sexual encounter was a little scary, 'cause I thought first of all, I thought- I wouldn't get turned on…then I thought this (breast implant) would all break. And you can't press it too hard. They pop. Not only would the incision open, but they'd pop…but, apparently, you can play football (be physically active) with them.

The establishment of the safety and durability of the breast implant provided an essential confidence. This woman joyfully resumed satisfactory sexual activity with her husband.

Planning for intimacy

While re-establishing sexual intimacy after breast cancer treatment was anticipated to be difficult, the women also remembered their ability to work out a plan if the opportunity arose for sexual encounters. Development of a strategic plan for physical intimacy weighed heavily in the thoughts of four women. These participants spoke of the readjustment to sexually intimate encounters with concerns about the secondary physical changes after the breast cancer treatment that included surgery, chemotherapy, anti-estrogen treatment and radiation. Preparation for sex after the breast cancer treatment included solutions of engaging in sex with the lights out. Strategies to accomplish this endeavor were exemplified in one woman's sex plan to avoid the disclosure of her breast's physical changes as, "doing it in the dark", manipulating clothing or the agreement that after surgery or radiation treatment breasts are "off limits". Struggling with the side effects of anti-estrogen treatment, a participant consulted with a provider from a holistic wellness center to whom she described her fears about abruptly discontinuing hormone replacement therapy. She said to this clinician, "I'm going through menopause again. I'm dying at night. I can't sleep. I'm sweating like a sieve…I'm really worried about losing my femininity…vaginal atrophy…I'm going to have painful sex." After the pivotal consultation and a prescription for vaginal suppositories, this participant was able to alleviate some of her perceived symptom barriers with plans for a successful and desirable engagement in coitus.

Pornography

In the case of one woman's sexual intimacy, the impact of her husband's addiction to on-line pornography became apparent after her breast cancer diagnosis and treatment. Although the details of her husband's addiction history were not disclosed

during the interview, she perceived its strong contribution to the insufficient fulfillment of her sexual appetite. The consequences of her husband's fixation with pornography on sexual intimacy preference was described as "I love it (sex) to be more, but it's not great and because my husband is a porn addict… he spends a lot of time in front of the computer…I just don't have much sex." Thoughts of the possibility of an extra-marital sexual encounter during an upcoming vacation to fulfill her sexual desire and appetite were entertained. A plan to achieve her sexual satisfaction goals was expressed in a sexual fantasy as,

> If I went to (vacation location) and met somebody down there…I would have no problem going to bed with him…I really don't have any big moral compass about that, especially since this is his (husband) choice, not mine. But the way my boobs look I don't think I'm going to, don't want to really take my clothes off (laughs). I could maybe shuffle things around.

In the case of this participant there was a dynamic tension between her need to fulfill her sexual appetite and a hesitation out of her fear of rejection of intimacy. As the interview progressed the ability for the participant to overcome this internal conflict was expressed when she said, "Well, if the incentive is there, hey, right?"

Beauty in the eyes of the significant other

The women's perception of wholeness and the appraisal of their beauty and desirability as seen through the eyes of their sexual partner was a powerful theme regarding the preservation of sexual intimacy. Frequently the women perceived that, from a man's perspective, the primary value of a woman is as a sexual partner. A participant who expressed this sentiment said, "I would love to fall in love again and have - and get married again. No man's going to want a woman that can't have sex." In contrast another woman reflected on the impact of surgical advancements that reduced disfigurement and barriers to sexual intimacy. Reflecting on the positive outcomes of her

surgery for breast cancer one participant exclaimed, “In the days of your grandmother, it was like oh, my God, we are ruined forever, massive scars and cavities here where your breast would be.” In contrast, this same participant demonstrated that the strength of her own marital bond was not affected by her bilateral mastectomy and immediate reconstruction. For her and her spouse, these surgeries did not pose an obstacle to their sexual intimacy. She said,

> I have plastic boobs...I’m just fine. It’s just fine (laughs). So that did not interfere in the long run with our intimacy or his appreciation for whatever loveliness he found in me…I mean we knew it was all artificial as far as intimacy and my sense of femininity, I’m fine.

However, not all of the women had such positive experiences. One woman recalled her husband’s response to her mastectomy as follows,

> I think he doesn’t want to look at me...(pauses) being mutilated…I’m sure that’s the term he would use…It took him a long time to look at my side where the mastectomy was. He still doesn’t really, you know, look at it that much.

Another participant whose husband’s gradual decline of engagement in intimacy and unwillingness to speak about or even look at her affected breast after her partial mastectomy articulated a sorrowful viewpoint of the impact of breast cancer and aging on sexuality and femininity as,

> It’s just loss after loss after loss after loss ‘til you have loss of your body. You have loss of, you know, with breast cancer, it is your femininity. Breasts are who you are as a woman…and sexuality…It’s unsightly, so, I don’t feel as pretty as I was before the surgery…your sexuality is going down because you have absolutely no libido, and you’re tired all the time.

The impact of the partner’s words and actions positively or negatively affected the participants’ self-perception of desirability and worth. Thus, overall, what the women of

this sample who were in a committed relationship saw reflected in their partners and husbands influenced their self-perception of beauty, value and wholeness.

Sexuality without a sexually intimate partner

Half of the participants reflected on reaching a place of acceptance of living life without a sexually intimate partner. The resolve to move on with life regardless of the presence or absence of an intimate companion was expressed as follows by one participant, "It might be where you're at the point where you just like to say, you can take it or leave it." In the eyes of these women the ability to look back on a long life filled with love enabled the transition of perspective regarding loss of intimacy and sexuality. As one woman described when she passionately reflected back on her life and how these experiences enhanced her ability to accept advancing age without sexual intimacy,

> I'm without a partner but I've had tons of love in my life. I would love to have another relationship but I'm not passing out for it…I am a sexual being…I've known love in its most beautiful way...I still carry it with me.

Advancing age gave the participants the ability to philosophically accept the loss along with the limited potential of a partner and move on with their lives. One participant described finding a place of contentment with these physical changes of aging in her life as, "Realistically, aging is about losing, you do lose something…it does limit my life…that's a limit which I've accepted…it works better for me to accept that than to fight it."

Wise sex educator

Connectedness to the next generation and the ability to offer sage advice and encouragement gratified the participants. A woman expressed her delight in her newfound role of wise older sex educator and relationship counselor after breast cancer, when younger men sought her advice on sexuality and intimate relationships. She chronicled her experience as follows,

> I demonstrate my understanding and a deep appreciation of sexuality by the counseling that I have. I mean I'm not a counselor, I'm just an elder but because I've been a community organizer for so long, I know a lot of people. … My kids laugh at this, as if by some wacko reason I have a steady stream of young guys I know and love who come here and just talk with me. It's so funny and they are single. They're looking for a partner…I'm not afraid to talk about sex.

This same participant finished her remarks by saying, "Eldering in my personal experience has been a blast."

In conclusion, experiencing sexuality for the women of this sample encompassed the formation of an ideal as a multidimensional connection with others. The maintenance and re-initiation of sexuality were problematic at times. Engaging in intimate encounters after the breast cancer necessitated strategizing for the activity for some women. This dynamic process of establishment normality required re-definition and re-establishment of the ideal due to the accumulation of losses from aging and breast cancer treatments. Life experiences enhanced the participants' acceptance of the re-definition of sexuality with the ability to negotiate intimacy and move forward to flourish.

Describing Femininity

Femininity was described as a dimension of intertwined ethereal (inner) and physical (outer) subthemes of being female and was deeply embedded in womanhood. Overall, the notion of femininity was an elusive, taken-for-granted concept that defied a concrete discrete definition for the majority of this sample of older women. The intertwinement of these dynamic inner and outer processes of femininity was evident in the data before and subsequent to the diagnosis of breast cancer. However, the diagnosis and treatment of the cancer threatened the women's existing self-perceptions of femininity. In the outer processes of femininity that pertained to reaching out to others, the data demonstrated an intentionality in the expression of femininity and the

interactions with significant others and society. Continuously adapting to new situations enabled these participants to move forward beyond their cancer experience. Moving forward included incorporating new aspects of femininity for some of the participants.

Inner Processes

Absence of formal education regarding femininity for this cohort of women aged 65 years and above resulted in dynamic inner processes devoid of concrete delineation or exemplars. Descriptions of the ethereal dimension of femininity were vibrant inner processes. The conceptualization and actualization were derived primarily from social observations and interactions with family, peers and society. Femininity for these participants was described as an absolute, elusive, inner beauty, a shared understanding. Masculinity and femininity were viewed as complementary. There was an intentional act, a desire to express femininity. In addition to the first subtheme, ethereal dimensions, the second subtheme that was evidenced was that femininity was threatened by the diagnosis of breast cancer.

Ethereal dimensions

Education. Receiving education on being a girl or regarding femininity was unspoken and occurred primarily through observations and social interactions. A participant who recalled that the topic of femininity was not part of daily conversation said, “I don’t know whether there was too much advice (laughs). I think it was more or less an observation.” Several participants shared that their mothers did not adequately prepare them for puberty. Girlfriends often provided information on menses, as in the following example,

> My mother was not good about those things…several girlfriends…I was 12 years old. We went to summer camp…all the girls were asked. “Are you menstruating?” When they asked me…I looked at my friend and I said “What does that mean? …

> ‘I don’t know whether I am or not”…she (my friend) said “No, she isn’t.” (quick laugh).

Disengagement with physical changes in the development of feminine features during puberty was evident. Although these participants were transitioning into womanhood, they remembered an intentional endeavor to avoid conversations or education of natural changes. One participant described maintaining secrecy of secondary physical changes as follows,

> We were all growing into our bodies…but it was really kind of a cloak over that part of life…being feminine…we didn’t talk about it. It was pretty much a secret when you got your period. Nobody knew.

Elusive. Femininity was an elusive concept that seemed bewildering for many of the participants to describe. Several women met the initial questions “What does femininity mean to you?” and “How would you define femininity?” with a burst of laughter and stated an inability or a lack of language to respond. The concept of femininity was neither what these participants dwelled on nor what was pondered on a daily basis. Imagery of femininity existed in the participants’ minds yet the women acknowledged it was difficult to describe or clearly delineate these mental impressions. As one woman reflected, “Females are usually more delicate and more in detail (pause) and you know (pause), I don’t know. I—I have a picture in my mind but I don’t know how to describe it.”

However, as the interview with this and the other participants progressed, richer descriptions of femininity emerged. Femininity included physical attributes such as being delicate, gentle and attentive to hair, skin, clothing and outward appearance, gracefulness and the whole physical gestalt of movement. The sentiments of femininity were echoed by a participant when she summarized the essence of femininity as, “Soft and sweet, like a ballerina, just beautiful hands, beautiful feet, lovely face.” In addition to these attributes, femininity was viewed as the overall way that one behaves and the

presentation of self. These diverse components of femininity that existed in each woman were frequently described as being a very feminine lady in some situations while she can select to be more casual in other settings.

There was a consensus among the participants of what did not constitute femininity. An example of such a consensus was regarding casual sex as illustrated in one woman's comment, "The blatant offering of quick sex that destroys the spirituality completely and make it just you know, another dish of ice cream. It's just like another way of entertainment. That is not femininity." Additionally, other aspects that were demarked as unfeminine included being insensitive to the needs of others, vulgarity and immodesty.

Beauty from the inside. Societal focus on the outward presence of the ideal feminine physique such as big breasts, small waist, thick flowing hair and delicate features opposed the descriptions of the significance of the ethereal inner essence of femininity. The evaluation of femininity, the women of the sample echoed, should instead be based on one's inner qualities as was expressed by a woman who said,

> A lot of people think that it (femininity) is all on the outside and how you look…I don't think that really and truly is what it is… it should be what kind of person you are from the inside and that should be the most important thing.

The unity of femininity as the reflection of beauty from the inside was the number one priority. This inside-outside unity was concisely conveyed by another participant when she said, "I would say looking pretty inside and out."

Masculinity and femininity as complementary. Like femininity, masculinity was also described as elusive and changing across time and geographic and societal boundaries. In women's effort to describe femininity, the concept was mostly contrasted with masculinity and described in absolute terms with perceptions of discrete differences between men and women. Participants contrasted the thought processes and social

conversations of men and women, such as sports versus family, stressing these differences, as signified by one woman who said, “I think men see things usually in a different light than we do. They see it from their perspective and it’s not always the same as ours.” Femininity inherently meant being a woman with all the elements, dimensions and characteristics possessed by females, as one participant confirmed, “I am feminine-I am female.”

However, masculinity was neither viewed as the opposite of femininity nor possessed only by those born as male individuals. Several women acknowledged that, when they think of a woman, it is someone who is relatively more feminine than masculine. Thus, despite the absoluteness of being either male or female, some women of the sample also perceived a variance of male or female traits and characteristics an individual portrays at a given time. Femininity was portrayed not as a war between the masculine and feminine dimensions of life, but instead as the complementary balance of male and female traits and characteristics along a continuum. Femininity was viewed as a complement to masculinity or to the male role and nature within the perspective of aging. One woman shared the amicable perspective of male and female as,

> I’m not a feminist. Even though…my whole career was in that period where we had to be like a man. I don’t believe that… I was in work in the ‘70s, and I always felt that I didn’t want anyone to give me a job because I was a female. I wanted them to give me a job because I was talented at what I did. So that kind of made me mad. I’ve since understood that, I think females can complement men. We have different characteristics that I think are important to make the world go ‘round.

Another participant, describing the complementary nature of feminine and masculine traits that she perceived in her daughter, said,

> There are some masculine traits in femininity, and then there are feminine traits

> in masculinity. I guess more behaviors that we think of behaviors that are masculine behaviors of being out in the working world, being strong, not letting people push you around or bully you, being intelligent and being able to use the intelligence, but also the physical characteristics, too.

The dimensions of femininity did not diminish either essences of male or female, both were simply part of nature created by a higher being or God. Women of the sample identified the capacity of non-linear thought processes as a unique characteristic of being female as exemplified by the woman who said,

> Women have a way of thinking that's almost spatial, in that we can put dinner on the table - timing the potato, the meat, and the vegetable. Whereas, a man is linear… they have to do one thing at a time… they particularly excel at computers and engineering. Because it is linear, and one thing goes to the next. Whereas we are multitasking or we see things in a spatial way.

Intentionality. Intentionality, a required effort or motivation at times to express the ethereal dimension of femininity, was echoed across the women of this sample. This desire and aspiration to personify a woman instead of a man meant that participants engaged in an active intentional choice of wearing apparel that society deemed feminine in texture, drape-ability, weight, color and style to create a feminine persona for the individual woman. As expressed by one participant as the juxtaposition of effort and intention in the quest to demonstrate femininity when she said, "Some women dress mannishly and I don't. I never have, never would. I don't want to. I want to be a woman. So, my clothes are all, they look like women's clothes …I'm just myself, I just live."

Throughout the data there were perceptions of feeling very feminine in simple casual comfortable attire that could be described as androgynous or masculine. One woman illustrated these feelings when she shared, "I'm more comfortable in a pair of jeans and a pair of Keds than I am sometimes when I dress up. But I still feel feminine in

them." Being less attentive about looking one's best or a relaxed adherence to social standards of "being a lady" in one's appearance was sometimes equated with self-reflections of feeling less feminine in comparison to other women. In one reflection a participant compared herself with other women when she stated, "I don't consider myself really feminine…I don't like the laces and I don't like the, all the dangling earrings and things like that. That's what I look at as a feminine lady."

The purposeful intent of femininity, the deliberate action to enhance physical characteristics and behaviors traditionally thought to be desirable for a woman, was a dynamic theme of acquisition and repression. Represented in an interview one woman recalled as a young adult making herself less attractive, feminine and desirable to men by cutting off her long, thick, beautiful hair after an uninvited kiss on the cheek while on a blind double date set up by a mutual friend. Hence with this intentional action she cut off an important aspect of what she perceived to be her femininity, freeing her to feel liberated while leaving desirability behind on the floor. The desire to be left alone and the withdrawal from femininity and womanhood was recounted after a long tearful pause as this participant looked off in the distance and said, "I cut my hair, my most beautiful aspect and I cut it all off. …I don't want to be feminine."

The women's perceptions of intentional acts of femininity were reinforced in the comments and actions of others. Often women did not see themselves as feminine but instead internalized compliments from others to gauge their feminine appearance. To overcome the barriers of negative self-perception of femininity, women spoke of the external validation of possessing feminine traits through reception of compliments on hair, dress, jewelry, nail polish or make-up as expressed by one woman, "I (laughs) don't know whether they do or not…I get compliments on clothes or jewelry or things like this…somebody complimented me on my nail polish…I thought gee this person was searching (laughs) for something to compliment." In opposition the participants

perceived men as having it a lot easier, noting the absence of preparatory effort or concern as illustrated by one participant, “I try to look a little nicer. I think that because men don’t, you know, they don’t care what they wear when they go out (laughs). They don’t care if they wear plaid with stripes (laughs).”

The intentional act of portraying femininity in an effort to appear pleasing to self, a mate and others was a defining element of femininity for these participants. Decorum related to aging and femininity encompassed the expectations of the changing times in the way women behave and act. In regards to her younger self, a participant reflected an example of an age-related femininity social grace convention when she said, “When I went to church you always wore a hat, white gloves and a nice dress. (I) always wore a hat and white gloves and looked like a lady, a young lady should.” Additionally, femininity was defined by one woman within the context of aging, “Women want to feel good about - we’re very conscious about our looks…that’s why we wear makeup…we exercise…we do all this stuff...we live in a society that values youth.”

Work on the composites of femininity to please the self and others did not solely require complicated upkeep of appearances. Femininity also meant the outer reflection of inner contentment. Depictions of someone as “ultra fem” integrated the way a woman physically looks and moves with grace and the mental capacity to accomplish greatness. This attainment was exemplified in the reflections by the participant who, when describing her daughter, smiled broadly, sat up regally and pronounced,

> When I think of femininity, I think of my daughter because she’s like ultra fem, and it’s not like she’s, what are they called “high maintenance.” It’s not that, it’s just the way she walks, carries herself, and how she has a long neck and just really smart and really beautiful and all of that and very capable too. So, I think... there was a wide range of femininity.

Threat to femininity

The breast cancer diagnosis and treatment consequences threatened femininity and caused anticipatory apprehension, anguish and guilt among the majority of this group of older participants. Recurrent inner thoughts of breasts being disfigured or lost occurred during the initial diagnostic and curative modalities. The ensuing imagined or authentic loss or alteration of femininity was additionally impacted by the perceptions of aging in the illustration by one woman when she said, “Aging is the enemy of femininity.” However, this same participant added the ability to hinder nature’s progression when she stated, “You can counteract aging by staying sharp and being good company and being able to move.” Despite this optimistic stance that was also shared by other participants, there was an inherent difference regarding aging on the maintenance of femininity in comparison to masculinity. This belief was reflected by one woman who said, **“**I think it’s easier to be an old man than to be an old woman, maybe the expectations are lower, I think that’s it.”

Six of the nine women on hormone replacement therapy at time of diagnoses said that they stopped the therapy based on a clinical recommendation at the initial suspicion of breast cancer. The loss of estrogen consequential to the immediate discontinuation of hormone replacement therapy and the initiation of anti-estrogen therapy for estrogen positive breast cancer were worrisome to these participants. Specifically, termination of the hormone estrogen equated to a loss of femininity for these six participants. Woeful thoughts arose regarding the anticipatory unwanted consequences of estrogen cessation on the maintenance of a woman’s youthful female appearance and demonstrative level of femininity. These turbulent thoughts regarding the motivation to have started the hormone replacement and the remorse of contributing to cancer was evident in one woman’s interview when she said,

I was raised with the idea, kind of the Roman, stoic idea, that, if you get ill or

have something that happens, it's more or less your fault. I did take a hormone replacement for 22 years. So, I did feel guilty about that. I stopped the day I was diagnosed. It was important to me…obviously…I thought it was important for (femininity) it just keeps - your skin's nicer, everything is nicer. Whereas, you go off it, and suddenly I aged immediately when I went off the hormones. You lose elasticity; you lose your firmness of your stomach muscles. You just, I mean, you just lose…hormone replacement (therapy) is great. It's just a way of extending youth…(that is) the big reason for taking it.

Outer Processes

Femininity was described as a dynamic interaction with self, others, culture and society. There were two overarching subthemes in the outer processes of reaching out to others. The first was a perceived threat that breast cancer brought to femininity as seen by others that included alteration of physical attributes that were viewed as stereotypically unfeminine. Lastly, societal norms, values and roles of femininity were influenced by the contextual expectations of time, culture and the transition into womanhood that guided the expression of femininity. Although the women easily identified hindrance of expressive behaviors of femininity in other cultures, recognition in the participants' identified cultural environment took time.

Threat to femininity

Unmasked. Across our sample, two important physical characteristics to discern gender, or male from female, were described as breasts and hair. The anticipated loss of hair, breast tissue and estrogen were considered part of the treatment outcomes for breast cancer. Thus, the diagnosis posed a potential threat to the physical attributes of femininity. These anticipated losses were poignantly identified by a woman who said, "The way you tell male from female in our culture…is your hair and your breasts…you get breast cancer, and you lose them both."

While hair loss equaled a loss of femininity in the social environment of the participants, societal views of hair thinning and loss differed between men and women. The women of this study voiced aggravation at the unwelcomed comments when men did not understand and made light of the impact of hair loss on women. Exasperation was expressed by one woman whose husband minimized the importance of her hair loss subsequent to treatment for breast cancer. This participant also demonstrated the threat of hair loss or thinning to her personal perception of femininity when she stated “Men go around bald all the time…you’re not a woman you don’t understand, it’s completely - you know, it’s it is part of your femininity.”

Pre-existing barriers. The three participants who characterized themselves as being tall expressed height as a pre-existing barrier to femininity because they were mistaken for men prior to the breast cancer diagnosis. Repeatedly these participants recalled instances of feeling self-conscious when out and about in public and being referred to as male subsequent to cancer treatment. For these women the potential loss of either hair or breasts as part of the treatment for breast cancer was perceived as particularly impactful on femininity. For one participant, the notion of the ideal feminine physique was partially attributed to the pin-ups of scantily clad, sensual women with flowing tousled hair on her father’s workshop walls. Although the perfect feminine figure mismatched her own physical characteristics during adolescence and young adulthood, her summation of surviving emotionally intact despite societal expectations was reflected as,

> Your view then of femininity was the very big breasted, very voluptuous female form, which we didn’t have. I mean, I was stick thin, very slow to develop, as was my sister…that was our growing up. We survived without too much trauma.

Husbands’ observations and positive comments of other women’s physiques were detrimental to the women’s self-perception of femininity. The impact of inappropriate

comments was exemplified in one husband's observations regarding other women's breasts. His adult female children attempted to dissuade him from this behavior, and eventually his wife disregarded or ignored the comments with the rationalization,

> He would comment on the, uh, uh, how some girl looks… he just will say, "She has really big knockers", or something like that and it's just crude. I just don't know where it comes from, but he has always been somebody who notices women's breasts…he's old (laughs).

Despite this woman's verbal normalization of her husband's lifelong nature and ongoing behavior to observe and comment on other women's physiques, the non-verbal gestures of this participant appeared mismatched. During the relating of the story, she looked over my shoulder into the distance, frowned as tears formed in her eyes, hesitated as if in thought and let out an explosive laugh to end the tale. Previously in the interview the same woman, who three years prior had undergone a unilateral mastectomy without reconstruction, said, "If my husband couldn't live with me without (breast) reconstruction, that was his problem not mine" illustrating the discordance of perceptions of feminine characteristics between the husband and wife.

Societal expressions of femininity

The women easily identified differences of femininity in others, and as the interviews progressed, self-identification became a simpler task. Self-identified characteristics, traits and behaviors of femininity were exemplified as being kind, caring and a caregiver while being self-centered, uncaring about other people and unconcerned if one's actions hurt others were described as unfeminine. While society may view inner and outer strengths, the willingness to speak up for self and others and being over six feet tall as negative traits opposing the perception of femininity, the women of this sample did not agree. For these women, who identified themselves as competent and successful, others misevaluated their personal strengths as unfeminine actions of

aggression. The diversity of femininity characteristics of the sample of women was encapsulated in the following summation of one woman,

> It means I am a woman. I think a woman's body is very beautiful and I think that, that being a woman is fun, but it's nice to be pretty and have your nails done and still be a competent human being...I'm an A-type so I think that's part of it. I'm not a perfectionist. Don't look inside my cabinets (laughs). But still I get the job done. I guess that's what I mean by competent.

Outward manifestations that were described as not feminine included non-participation in the self-care activities of dressing up, polishing nails, fixing hair, and wearing earrings. Another behavior that was noted to distinguish femininity was characterized as being a respectful conversationalist. A participant described these outward characteristics as opposed to the actions of her daughter who talked, dressed and carried herself like a "truck driver". She described the impression that her daughter gave as follows,

> I get upset with my daughter because, to me, I don't think she is very feminine. She is more of a guy 'cause just how she carries herself and how she talks, and I don't like the words she uses sometimes and how insensitive and belligerent she can be sometimes.

Thus, actions of being abrasive and accusatory were viewed as unfeminine behaviors. Later in the interview, the same participant saw her daughter's insensitivity to others as not caring and not being a spiritually good individual. Additionally, she described her daughter as being rude and mean, "It's like there's a sensitivity chip that's missing as far as being feminine and a woman, and nurturing." These unfeminine characteristics and behaviors were a source of conflict and tension between these two women.

Women were perceived as being socially intimate and focused on communication while men communicated while doing something such as watching sports. This need of women to talk with other women to form and maintain social bonds

of encouragement and support was common in the data as exemplified by one participant who said,

> Women need to talk to other women or people in general much more than men do. Men don't. Well, my impression is that they are not looking for somebody to talk with as much as women are. Women need support, supportive exchange, let's say, and you can get that from men but it's much easier talking with other women. They know what you are talking about.

Changing gender roles over time

A lack of variation in societal expectations of the gender roles existed for this sample of women in the formative years of their youth and young adulthood. Traditional gender roles when men earned the household money and women performed the household and child-rearing duties were easy to differentiate for the majority of participants. A simpler time in life occurred during the women's' youth, described as "in my mother's day," was reflected as a time of beauty and balance between the elements when the gender roles were easy to define and identify. A woman did not work and earn money outside the home, but instead her life ideally was comprised of having a man to love and respect her. In a poignant reflection one participant described that her father dismissed her mother's career as a hobby, "It's like in my mother's day (laughs) women didn't hardly work outside the home…when she (mother) did…my dad kinda poo-pooed it as just fun…it hurt her feelings that dad didn't think of it as serious." Thus, this participant recalled her mother's hurt feelings because her husband did not take her career seriously.

In their younger years, these participants characterized the behavioral expectations around femininity as being educated, polite, and sitting like a lady, showing class and being well behaved. The women recalled expectations that girls wore dresses all the time to meet the expectation to dress up, only wearing pants under dresses when

it was cold outside. A cherished memory for one woman was dressing up and getting her hair done to go out to dinner with the family. She described changes in her current behavior, as women no longer go to the beauty parlor to get their hair done. These shifts in societal expectations were observed as modifications of femininity and an acknowledgment that not all alterations are good. Likewise, losing some femininity while gaining personal power was also expressed by some such as the participant who said, “I think part of our femininity went away with the extra power maybe that we got.” One woman identified the changes in the focus of femininity when she described the different priorities she has observed in modern women and, like other participants, voiced a desire of current society to reestablish former norms of femininity. She said,

> Women are more worried about being sexy than being educated…Maybe I am old fashioned (laughs) education, being polite, sit down properly and all the things that they teach us and I tried to teach our girls now…you have to be showing class, education, well behaved.

Femininity was currently viewed as ambiguous due to modifications of traditional gender roles in current society. More variation, tolerance, acceptance and exhibition of non-traditional roles for both men and women in opposition to the stringently adhered to roles of childhood were recognized across participants. Men staying home to raise children and women being the financial breadwinner of the family were welcomed changes. Personal experiences with role changes included a stepdaughter who barbecues and mows the lawn. Additionally, the women encountered situations based on past cultural expectations as the participant who asked her husband, “Why can’t you fix things like my dad?”

Over the decades the dynamic power acquisition of this sample of women resulted in being mindful of feminine expression. Adaptation of femininity was seen as a requirement to suppress outward beauty to overcome harassment. The double-edged

sword of feeling and looking beautiful could result in being victimized, receiving unwanted sexual advances or harassment, as evidenced when one participant said,

> That is degrading. It takes away, you know, you're feeling good in yourself and you want to look beautiful, but then, what, you feel guilty because then you look beautiful and it's your fault that they want to manhandle you? You know, it's wrong. It's just wrong.

The work force was seen as a "man's world" by the women who echoed that the ability to attain respect equated to women receiving equal salaries in employment. The attainment of respect was an essential component to flourish as a woman as was reflected by one participant who said, "To be feminine and beautiful you have to be respected…if you don't feel respect, I don't know how the rest can blossom." While respect was considered essential, sexual harassment denied women respect. Many of the women acknowledged their value in the workplace and world as that they deserved to be valued for their natural ability to take on more and accomplish multiple tasks at the same time.

The participants also described the difficulty of being feminine in today's culture due to the acquired freedoms of choice in education, finance and employment. Inabilities to reconcile personal desires with societal influences that permeated expectations were described as making it difficult to successfully fulfill both traditional gender roles for the family. One woman compellingly described this accommodation of ideals as,

> When I held my first little baby in my arms, I thought, there is no way, I cannot do both. I will not do both. I do not want someone else to raise my little girl. So I stayed home and that was hard…my paycheck was bigger than my husband's at the time and to stop that was like - cause I thought the paycheck was an affirmation of how good and talented I was…that was my barometer to say I am worth something and then suddenly I am not worth anything.

Another change over the years was that expectations and responsibilities of female children had changed. One woman recalled being left at home alone at nine years of age to care for an infant sibling for several days. In contrast, current societal expectations required constant adult supervision of all children's activities. Currently the planned agenda of the entire week and life of the child was seen as the central focus of the parents' social lives. This rigidly controlled schedule was very different than the participants' experience and was described as a restriction in children's freedom.

Cultural stereotypes

An open-ended question invited the participants to share their views on femininity as expressed in women from a culture or race other than their own. Abundant variables of social circles, customs and environments were perceived to have shaped the cultural stereotypes of femininity. Identification of diversity in femininity across cultures, geographic locations and religious affiliations existed within the perceptions of the older women of the study.

Women who did not self-identify their race or cultural heritage as Asian described Asian women as exceptionally feminine despite perceived restrictive cultural roles and freedoms. Actions of being submissive, demure, essentially honoring and obeying men were aspects of the demonstrative custom of femininity as reflected by a participant who said,

> The man is the head of the house (in Asian cultures), the one that gives all the orders…it's like they're (woman) the submissive one. The wife was just there to serve the man. So, you have to be behind me and I am the king bee or whatever.

A participant admired that despite the discrimination and hardships of the internment camps, her Japanese American friends' cultural social graces endured and were passed along in the boys' and girls' clubs. Social graces were described as qualities that equated with the enhancement of femininity when one participant shared,

> They (Asian women) have a lot of, I don't even know how to describe it, but social graces…they are just very warm…never at a loss for words…greet people…talk at length about your children or grandchildren or whatever they are just very good at that. They are very socially adept.

Additionally, the characterization of feminine traits of the Southern Belles' social grace and charm was described as comparable to Asian women when the same participant added, "If you think of a Southern Belle…some of that social graciousness and skill is a part of femininity."

Muslim friends of participants were members of Islam, a religious group that was perceived as more rigid and less tolerant of change to traditional gender roles of male and female. Expressions of femininity in the Islamic religious culture were identified as being more restrictive. Perceptions of the Islamic society included loss of freedoms, subservience and inferiority to men. Loss of freedoms within the perceived governance of females by male family members was characterized in the expected adherence to cultural and religious dogmas of thoughts and behaviors. The display of a woman's face or body was prohibited as being too disclosive which necessitated the wearing of a burqa or purdah. The participants perceived the Muslim women's feminine expression was suppressed. One participant reflected, "People who has to cover their hair or the people who has to use cover of themselves…it's like annulling-annulling the women completely."

The experience of staying in an Islamic household illuminated one woman's viewpoint of the dramatic difference in the environment when males were present. The vivid contrast was described as abundant laughter, lighthearted conversation and carefree activity when women and children occupied the household alone, but the scene drastically changed with the sudden arrival of males. As recounted by this woman who interacted with Muslim women through business associates,

> The ladies that I met that were Muslim…One time, we went to a family, and the girl was covered…my husband left with her husband…she took immediately all the things out (coverings)…we were talking, eating, she was moving in the house and the children…I really don't know how she knew her husband and my husband was coming, and in a second she was running and putting everything back again...it's a domination.

Reflections from two additional participants were shared about primary school classmates and a daughter's best friend who, as practicing Muslims, needed to change their physical apparel after a certain age due to the cultural and religious beliefs of Islam. Additionally, there were recollections of girls being forced into arranged marriages at 12 years of age and subsequently getting married immediately after high school graduation. The requirement of covering hair and body whenever in public was perceived by the participants as a hardship and removal of freedom as expressed by one woman, "Devout Muslims were in full purdah…head to toe and you never-never saw them. They had no freedoms, I guess." The constraint of a requisite constant escort and physical cloaking of Muslim women were perceived as repression of femininity and rendering the women devoid of choices outside of the home.

The popular embodiment of femininity and stereotypical seductress exemplified the exploitation of femininity for self-promotion. In current United States culture this sentiment was shared by one participant, "In our culture, I think feminine means sexy…big boobs and sultry behavior…using your feminine wiles. That's the thing that it's hard to balance this abuse thing. Because some women use that to their benefit." In opposition, possession of a mind meant not having to seduce others, which distinguished women who seduce as "other" or us versus them. As the same participant elaborated, "Women have done that for eons, being the seductress. I feel very separated from that because I felt like I had a mind, and I did not need to do that. It's just that that's

not me. That's not who I am."

Transition into womanhood

Memory of an event that marked the transition from girlhood into womanhood could not be easily defined across participants. That is, the women did not identify the demarcation of womanhood with the occurrence of menarche, physical development of breasts or puberty. Instead, the participants saw the gradual transition of womanhood in a chronological context over time, marking the entrance into womanhood in a later phase of life such as college, living independently or becoming a mother. For one woman the transition to womanhood transpired during her 30's with attainment of feeling very confident, beautiful and vibrant.

No participant discussed menarche prior to the initiation of menses. Several women remembered that the arrival of menarche was mildly traumatic since they were not prepared for menses until the actual event. Several women also recalled their mother providing written material or learning about reproductive health in school. However, the subject of menarche was covered up, cloaked in secrecy equal to other sensitive topics such as mental illness, family dysfunction and cancer. The women recalled being told about menarche once it happened, not before, but after the fact. There were recollections of learning the facts of life from other girls such as an older neighbor girlfriend who answered the following question from the participant when she had her first menstruation, "My gosh. Where did that blood come from?" The friend replied, "Well, now, look. I'm going to (clapping hands for emphasis) sit you down and tell you the facts of life.*"* Thus, this woman exemplified others in the sample that felt unprepared for the occasion of menarche.

Familial responses to menarche varied for this sample. One woman recalled an indication of having a more liberal father who would purchase the feminine hygiene products or supplies for the family at the local store. Her father was not embarrassed to

purchase all the products for the entire household of seven women. Other women remembered requesting feminine products from their mothers, never purchasing feminine products for self as a teenager or young adult. While the parents supplied the personal products there was sometimes a lack of empathy regarding the physical discomforts of menses. One woman recalled her mother as unsympathetic about physical ills of menstrual cramps. Hence, this participant hated being "sick" secondary to menses since staying home meant taking on menial tasks like "matching socks" as she sorted out the clean laundry.

Menarche symbolized fertility, not becoming a woman, and initiated a new rite of passage for the younger generation of women celebrating menarche. One participant spontaneously shared the significance of the event of menarche for her eldest daughter as,

> We made a big deal about it (menses) when (name of eldest daughter) got her period. I got her a rose, we made a special dinner and we had a celebration, Dad almost cried (laughs). Well not that they were a woman…now they can conceive.

However, the cessation of menstruation did not erase the title of being a woman. These women 65 years and older were thankful they no longer menstruated. Additionally, some women felt more confident after menopausal weight gain with the enlargement of breasts. For one woman the enlargement of breasts equaled acquisition of self-confidence. As evidenced in her statement, "I just wasn't as self-conscious anymore."

Development of secondary sex characteristics of breasts, defined waist or hips were not identified by the participants during the interviews when asked to recall an event or memory about the transition from girlhood to womanhood. However, the women spoke of an appreciation of breasts and possessing a feminine physique. As seen in the story of one woman's vibrant memory,

> I had one-piece bathing suits and then I went shopping and I bought a two-piece bathing suit. I had pictures of me…posing like this (laughs while putting right hand behind head, left hand on hip, arching back and smiling widely)...I felt like I was Rita Hayworth at least (laughter)…kind of a hot number.

Motherhood was esteemed as a privilege, responsibility, spiritual calling, and the honor of the giver of life, and nurturer were equated to the ultimate of being a woman according to the participants of the study. The birth of a child and embracing the miraculous dimensions of motherhood accounted for entrance into womanhood. One woman joyfully shared the fulfillment of her role when she said, *"*When I had my first child, that's when I felt I was a woman, not a girl anymore (smiling broadly)." For one woman the anticipation of being a mother was a life goal yet she painfully recounted the sorrow over the death of her child, noting that the loss of a child is one of the most awful experiences of life. Motherhood offered an exaltation of femininity in the experience of breastfeeding as expressed in the story of one woman, *"*What made me feel the most feminine is when I was nursing my baby, and my husband was there with me, you know that was what a woman was the ultimate…very bliss.*"*

Moving Forward

The final outer processes of moving forward past the breast cancer diagnosis and treatment employed continuous adaptation to circumstances that enabled the women to incorporate new aspects of femininity. The availability, meaning and understanding of emotional support, the significance of reconstructive surgery, sexuality and femininity discussions with health care providers, the appraisal and preservation of femininity and the role of wise older woman were the identified subthemes of moving forward. Instrumental individuals, emotional outcomes of support and surgical interventions, and the assessment of femininity along with the esteemed roles of older women enhanced the women's ability to move past the diagnosis in the preservation of

femininity in both the ethereal and physical worlds. In the last transitional subtheme recurrent thoughts of death were described, which superseded femininity concerns for a small subgroup of participants.

Emotional support after the diagnosis

Women overall were described as more open to talking about their emotional needs when spontaneously compared with men who were seen as more reticent in seeking emotional support after a cancer diagnosis. Across participants the bonds of friendship that were forged in the discussion of shared experiences of cancer treatment and outcomes were valued. Not only did the women find empathy through mutual sharing with fellow survivors during the acute phase of breast cancer treatment, but they also described that such interactions brought a renewed spirit for living.

Specifically, the need for emotional support groups for women was shared as expressed by a participant who recounted that sharing feelings and experiences was essential for her well-being, “Women in general are more open to talking about their emotions. How things make them feel and even their physical bodies…I think they do better maybe in support groups. You need support. You can’t do it alone.” Another participant joyfully expressed gratitude for organizations that supported breast cancer survivors’ emotional and physical needs when she stated,

> I have to thank (name of organization), is an organization that is helping breast cancer surviving women…they give seminars where they pay for everything…for three days – hotel and food and yoga and conferences. It’s wonderful…they gave us a day of beauty…they studied your skin color, your texture, your age too…they took professional pictures…we looked so beautiful, really beautiful, it’s good…with that experience, ever since then…I got very depressed with the cancer and I was not using, barely lipstick sometimes. So with this, lift up my spirit…made me feel good again.

Emotional outcomes of reconstructive surgery

In our sample 4 out of the 19 women underwent reconstructive surgery of breast tissue. All four women of this subgroup spontaneously spoke about the meaning of the revision of a mastectomy scar or the results of plastic surgery had on their self-perceptions of femininity. One woman who experienced her surgical incision as unsightly voiced how she alone appreciated the subtle change in the appearance of breast tissue after a revision of her lumpectomy scar. As she repositioned herself to sit erect in her chair and beamed, the participant communicated her enthusiasm as she shared her thoughts,

> I had this big ugly scar here (pointing to the place of the lumpectomy). It kind of sagged…he (surgeon) did a little plastic surgery…I just love him (surgeon) for that. It looks halfway decent again now (laughs) it didn't bother me…no one – he (husband) doesn't look at my breasts. But I could see it …I like it better because it looks better…that's the feminine in me coming out (laughs).

The remaining three women discussed their experiences with reconstruction of breast tissue, specifically with breast implants and autologous flap procedures. The final outcomes resulted in positive affirmations as shared by one of these women who had a bilateral mastectomy,

> I'm totally happy. I'm exquisitely happy. It was traumatic. It was terrifying for my husband because he thought that I would look, you know, with a big bloody scar and you know, that's not exactly beautiful to look at. So, he was amazed at how well put together (my breasts) I have been.

On the other hand, another of the four women had originally encountered a decrease in feelings of femininity as a consequence of reconstruction following a bilateral mastectomy. She relayed emotions of betrayal and misery as,

> The experience was terrible…I told the doctor, "Please, make them the smallest

> possible.” He made it double D. I was so upset, because they were huge! Believe me. I’m not lying. I was very, very unhappy… huge and ugly, bad and worse than ever…dealing with cancer and with these ugly breasts… It was murder what he did on me…nothing feminine at all.

Despite the sense of betrayal this participant felt, her response to the circumstances was to find another surgeon to revise the reconstruction. Her account of the positive outcome of her revision surgery heightened her feelings of femininity which was expressed when she reported,

> I feel so good…Even though I don’t have a husband, but to be feminine, you don’t have to be unhappy with your own body…We have to love our body, that the way God gave us, and that’s perfect…Even though if nobody sees them, every time you see yourself, put yourself down with the way you look, and you are not happy.

Sexuality and femininity discussions with health care providers

When the participants were asked about sexuality and femininity discussions with their health care providers all the women were in agreement that these professionals did not initiate conversations regarding sexuality or femininity. That is, at the time of the study interview, none of the participants’ oncology physicians, nurses or other individuals in allied health care, initiated a conversation regarding sexuality or femininity. One woman who shared this stark reality said,

> Doctors don’t ask that…“How are things going, sexually?”...They never ask that question. They just don’t ask…It’s really sad, because we are all sexual beings, and just because you have this disease (cancer), it shouldn’t mean that that part of your life no longer exists.

One woman recalled the only sexuality questions or inquiries occurred when she went for her annual routine gynecological and clinical breast exam as a written health

questionnaire given to her while she was in the waiting room prior to the clinical exam. The questionnaire contained questions about general health changes and sexual activity. However, these questions were not asked verbally, neither were her responses to these questions followed up during the clinical appointment.

Participants perceived that they themselves would have to bring up the topic since no oncology provider initiated a discussion or provided information. Only one woman initiated the topic of sexuality and femininity concerns with her primary care provider at the time of diagnosis. Instead of seeking information in the oncology setting other women sought knowledge about sexuality and femininity issues at outside treatment institutions unbeknownst to the oncology care team. One of these women found a clinic and seminar outside of the oncology setting to answer her questions and provide medical interventions to address her fears regarding vaginal dryness and atrophy. Some of the options that she discovered at this seminar were homeopathic regimens and surgical interventions, and she was very excited about the revelations of available help. Yet, the same woman admitted that she did not share her quest to find solutions and the discovery of interventions with her oncologist. Confident her oncologist would approve of the interventions to alleviate her vaginal symptoms she shared her thoughts of non-disclosure of the information as, “I did go to that (name of holistic) center for health and get the suppositories (for menopausal symptoms). I haven’t talked with my surgical oncologist about that. I’m sure she would be supportive of it.”

In contrast to the participants themselves, their husbands brought up the topic of engagement in sexual activity and intercourse during a few of the woman’s treatment and clinic follow-up appointments. As one participant recalled her first surgical consultation after the diagnosis of breast cancer when her husband said, “Oh! What about sex (laughs)?” These participants saw the question of continuation of or return to sexual activity as more on a man’s mind than on a woman’s mind. During the interviews

the women spontaneously offered that, if instruction about resuming sexual activity after treatment or reconstruction was ever provided, it was vague and non-specific. In the case of one couple, the husband questioned the surgeon at a postoperative appointment about returning to sexual activity at the completion of therapies and was told they could participate in recreational activities. She shared that he said, “You can do all sorts of things – ski, jump around.” This ambiguous instruction left the participant and her husband wondering if they could safely return to sexual activity since the topic of sex was not directly addressed nor were their questions answered.

According to some un-partnered participants, no sexuality questions were asked because of partner status at the time of breast cancer diagnosis and or treatment, giving credence to the assumption that only women with partners would have questions about sexuality. This assumption was demonstrated when one participant answered the question if anyone discussed sexual concerns with her after the diagnosis as, “We (health care provider and myself) never went there. Maybe, too, because they (provider) knew me and I didn’t have a partner to even kinda think about sex.”

When specifically asked about the ideal dissemination of information regarding the topic of sexuality, most women, both partnered and un-partnered, noted the importance of timing and delivery. The women felt that receiving the information after the primary treatment had finished would have been ideal. Furthermore, most women identified that they would have felt most comfortable with a female health care provider asking questions and giving the sexuality and femininity information. *“*I don’t know that I would be comfortable discussing it with him (oncologist). I’d rather discuss it with a female nurse*.”* The women of the study identified seminars, support groups and breast cancer supportive organizations where invited lecturers provided recommendations and encouraged the participants to have open discussions regarding sexuality and femininity within the group setting. Additionally, the lecturers identified the importance of

discussions about sexual concerns and prompted the women to initiate the conversations with their health care professionals, romantic partners and other survivors.

Appraisal and preservation of femininity

Overall, for this sample of women the experience with breast cancer was appraised as not having a negative impact on femininity. Participants responded to interview questions regarding the consequences of breast cancer on femininity as negligible. The ability to move unscathed past the encounter with breast cancer was affirmed by one woman when she said, "Pretty much the same. It hasn't affected my femininity or anything like that." The participants felt whole and all together both in the way others perceived them and in their self-perception. This impact of breast cancer on femininity was summarized by one participant who declared, "I still am happy in my heart and I feel good inside… whole and beautiful...I don't think I have a lot of negativity, where it's (breast cancer) made me feel less feminine than I did before I had it (breast cancer) because I am all together."

Possession of breast tissue, native or artificial, enhanced the femininity for the participants as reflected in a straightforward statement made by one woman when she reflected as follows, "I think maybe because I still have both my breasts, I don't feel less than a woman." Several women spoke of a good outcome on femininity in that the surgery did not leave them with scarred or disfigured breasts as was emphatically stated by one woman, "Not being disfigured…a scar across your chest or a part of your breast missing." Additionally, the same woman articulated later in the interview, "Obviously…especially from a woman's viewpoint, our breasts are very special to us because it's what makes us look female."

Seeing the continuance of desirability through her husband's eyes enhanced the preservation of femininity for some participants. Remembering a vital interaction with her husband was expressed by one woman's joyful recounting of his declaration, "I didn't

marry you for your breasts…I just love you, all of you." She concluded that, "He didn't marry me for my breasts. He married me for me." For another participant the positive outcome of reconstruction on femininity added to her sense of desirability. She said, "I felt more feminine after the treatment, because I had breasts…appealing to my husband…I look in the mirror, I see me. But this helped me be more feminine, number one, and also feel younger."

Desirability to men for the unmarried women of the sample also demonstrated preservation of femininity moving beyond the breast cancer diagnosis and treatment. Being asked out on dates was reassuring evidence that femininity remained intact as shared by one woman, *"*There are four men here that have asked me out…It's kind of reassuring that my femininity is there and it's appreciated*."* Popularity of online dating sites and availability of eligible romantic partners nationally and locally further restored confidence in her desirability as a woman. Another woman shared her experience as, "I went on that dating thing (name of online dating site)…I didn't realize …guys was coming out of the woodwork…my sister said 'Go for it girl!'" Admiration and appreciation from male suitors that reinforced the sense of preservation of femininity was articulated in the data. One woman communicated her appreciation of adoration when she said, "To have a man think that you look beautiful or tell you, you look beautiful is probably one of the most rewarding things you can feel, to make you feel really good about yourself*."*

The preservation of femininity in the context of aging and breast cancer was eloquently and reassuringly addressed by one woman in her eighties who said, "Just because you're, 80 or 90 doesn't that mean you're lost being a woman*."* The forthright ability of this age cohort of women to confront challenges with vigor and humor was shared by one woman as, "I'm a widow that wears stilettos, and I'm going to wear it. I'm not going to be walking around like a little old lady. High heels, really sexy high heels*."*

Role of wise older woman

All the participants collectively spoke of love, joy and happiness in being a woman, openly embracing the multidimensional nature that comprises the everyday and miraculous aspects of womanhood. Often the women spontaneously remarked on being distinguished as a confidante and mentor in the role of a wise older woman. Women found trustworthiness of their integrity reflected in the confidences others shared with the participant alone, singling her out as a worthy confidante. One valued aspect was coaching the next generation in the comprehensive life span from cradle to grave. Frequently advising others who sought the older woman's advice on relationships, sexuality and world affairs, and the dissemination of vital personally acquired knowledge about the nature of masculine and feminine roles in the family was an esteemed responsibility. Furthermore, one woman felt obligated to take political action in regard to civic affairs to maintain the "sacred" role of women in the family, community and world. When elaborating on her role to educate the next generation she reflected on the discourse and demise of sexuality, femininity and the sacred role of women in society as follows, "I wrote a documentary film series…we're out here to tell the truth as much as we can, educate, you know the, the political discourse." One participant passionately summarized the responsibility of a wise older woman to preserve the sanctity of femininity and motherhood as,

> I have always held this great sense of gift that I'm a woman and I have the privilege to measure into, to that privileged world of femininity and mothering. So I regret when some of my younger colleagues have refused to have babies, have children, because they are terrified of what would happen. I'm thinking, you're missing the whole point. I'm pretty clear about what I feel about being a woman.

Teaching their sons and grandsons about femininity included how to treat women in their social circles such as the chivalrous behaviors of opening doors, showing courtesy or

attentiveness toward females. One woman illustrated the importance of starting the education process early in life,

> Already I'm telling my little grandson - who is three and a half…you cannot bite women…you don't hit your mother…I'm starting with civility and manners…for my son…getting out of college, I said, "No matter what they tell you, always help women. Open a door for a woman. Put your hand behind her back." All those chivalrous things, I think are lost.

Furthermore, family members, pop culture and religious affiliations dictated a list of do's and don'ts on the expression of femininity. A benefit of being a wise older woman included the ability to share the meaning and expression of femininity and that men and women were created differently with specific distinct natures. One woman referenced the animal kingdom to illustrate the differences of male and female roles in the family or society as an exemplar for her children and grandchildren. The model she shared was the following,

> The female wolf nurtures and protects the baby wolf for two years. Then the male wolf comes in and takes that two-year-old wolf out to hunt and provide…and in the human family, that happens between birth and 12-13 years old. The woman is really nurturing and taking care of that child…then the father comes in at around that time in the early teens, and then teaches them.

Persistent thoughts of death

A subgroup of three women of the sample voiced persistent thoughts of death and uncertainty regarding breast cancer, which lingered after the completion of treatment. One woman characterized life level interference with recurrent thoughts of possible metastatic disease chemotherapy treatment. The fear of recurrence haunted her composure with thoughts of her mortality as opposed to femininity when she shared,

> It (breast cancer) just bothers me more, I think, about it on a life level than more on a (level) it's messed with my femininity…if it goes to another part of my body…they tell me, "Okay you have to have chemotherapy…if you don't, you're going to die.

Another participant shared how the persistent thoughts of death overshadowed femininity issues in her endeavor to regain normality and interaction with others as, "We feel different, and we try to be normal again...in the way that I feel less feminine. I didn't feel, but I was more concerned on the way people look at me like I was dying."

Summary

For this cohort of women, the preservation of femininity was challenged by the diagnosis and treatment of breast cancer. The ethereal and physical dimensions of femininity were formulated in the continual negotiation of inner and outer processes of social interactions and observations of others during the formative years and beyond. Self-expression of femininity equated to feeling comfortable with self, an inherent reflection of both inner and outer contentment with an ability to balance traditional masculine and feminine behaviors, characteristics and roles. The shared understanding of femininity across the participants co-existed with an acknowledgment of variations between individual women. Despite the threat that breast cancer diagnosis and treatment posed, the women 65 years and above built on their previous life experiences to adapt with resilience and move forward to embrace life to the fullest.

Chapter 6: Discussion

The unique experiences and perceptions of sexuality and femininity of older women subsequent to the diagnosis of early stage breast cancer are unspoken, overlooked, neglected and underexplored in clinical settings and the scientific literature. Essential to implementing appropriate change is the acknowledgment and understanding of sexuality and femininity from the distinctive knowledge base, worldview and voices of older women. Health care professionals, family, friends and the community at large must be aware of the provocative viewpoint from the voices of these older women to identify and provide for their unique care needs. The dissemination of knowledge from this novel subjective perspective will impact the largest age group of breast cancer survivors.

Qualitative description (Sandelowski, 2000; Sandelowski, 2010), with a constructivist grounded theory framework for data collection and analysis (Charmaz, 2014), was used to guide the study. Systematic analysis organized the data into three overarching themes: receiving the diagnosis, experiencing sexuality and describing femininity. Each of these themes was subsequently organized into three subthemes: inner processes, outer processes and moving forward. This chapter includes a summary of the key findings, comparison of findings with current literature, strengths and limitations of the study, clinical implications, recommendations for future research and a conclusion of the overall contribution of this work.

Summary of Key Findings

In the first subtheme of inner processes the participants described their understanding, meaning and personalization of the established foundations of sexuality and femininity. Receiving the diagnosis of breast cancer created disequilibrium with feelings of shock and thoughts of violent imagery and disfigurement. In their early formative years, education about sexuality resulted in limited knowledge about coitus,

reproduction and sexual intimacy that served as a poor guide for future sexual experiences. The convergence of breast cancer, sexuality and aging were embedded within established sexual behavior taboos and societal values. The ethereal elusive dimension of femininity was encapsulated within the participants' minds formulated through observations and social interactions. Femininity was described as the ethereal inner essence, which the women intentionally portrayed despite the threat that breast cancer posed.

Outer processes, the second subtheme, encompassed the interactions between the participants and various individuals in their environment subsequent to the diagnosis of breast cancer. Many of the women sought the assistance of others to help with the impact of breast cancer. These interactions were focused on the timeliness of disclosure of the diagnosis, information acquisition and support. This sample of women viewed sexuality as multidimensional, which physically, emotionally and spiritually connected them intimately with other people. Expressions of femininity were evidenced as robust interactions with others within dynamic cultural norms. However, these manifestations of femininity were hindered by both pre-existing and newly acquired physical and biological changes following the diagnosis of breast cancer.

Moving forward past the diagnosis, the final subtheme, involved re-establishment of normality for the women. The shock of the diagnosis brought the acknowledgment that cancer can happen to anyone. This understanding allowed the transition of thought processes from death back to life as an essential step to place the cancer diagnosis in perspective. Recognition of perceived and actual barriers to sexuality, sexual intimacy and femininity for both partnered and un-partnered women enabled them to find a place of fulfillment in an ever-evolving new normal. The processes of moving forward to normality were either enhanced or hindered by the availability of supportive services to address the unique needs of these older women.

Discussion of Subthemes and Comparison with Existing Literature

Inner Processes

Despite the progress made in treating cancer, a recent study conducted in the United States and the United Kingdom showed that the fear of a cancer diagnosis remains one of the most prevalent, unpleasant and troublesome emotions associated with disease-related concerns (Vrinten et al., 2015). The association between cancer and death is well established. Yet, as a clinician I was surprised to find that an early breast cancer diagnosis was spontaneously associated with thoughts of death that lingered and haunted some of the participants. From my clinical mindset early breast cancer was a treatable and survivable disease with an excellent prognosis. Therefore, when I started this research, I had assumed older women would experience early breast cancer without further trepidation after treatment completion.

Many individuals view cancer as an enemy that brings to mind fears of incapacitation and death (Vrinten et al., 2017). A few participants also described that they had experienced significant fears of violent imagery and disfigurement. The trauma and terrifying aspects of the breast cancer diagnosis and treatment were expressed as a violent attack on the body. Some participants described the experience as hacking off body parts, mutilation and the fear of being scarred for life.

In a recent study done in the United Kingdom, women openly described the fears, distress, shock and feelings of loss of femininity when they first looked at the breast after a mastectomy or breast reconstruction (Paraskeva et al., 2019). However, the women of our sample, who all underwent either a lumpectomy or a mastectomy, did not describe such emotions after surgery. In contrast, our participants spontaneously narrated the fearful anticipation of treatment outcomes as violent acts on the body with resultant disfigurement when they were initially diagnosed. These treatment consequences were seen as taking away the physical aspects that identified them as

women, specifically breasts, which threatened their expressions of sexuality and femininity. The significance of the anticipatory violent imagery or terror at the time of diagnosis has not been previously identified or described by older women. This may be linked to the common misperception that body image and physical appearance become less important to self-esteem among women aged 65 or more years (Baker & Gringart, 2009).

Events such as body changes or cancer screening exacerbated distress and fear of cancer recurrence among breast cancer survivors (Soriano et al., 2019). Women age 21-60 years overestimated their risk of breast cancer recurrence by as much as four times, despite the awareness that this contradicted medical providers' estimates (Kaiser et al., 2019). The consequential lingering despair, anxiety and fears of recurrence were similarly described by the women of our sample as expressed by one woman who said, "Once it (cancer) starts it never ends."

At times loss of hair and breast tissue associated with treatments necessitated re-evaluation and reconciliation of the women's ideal of sexuality and femininity within the context of aging. On reflection the participants described these changes as larger obstacles than they had anticipated. This dynamic process encompassed reflections of self, perceptions of the way others viewed them and the evaluation of society's ideals for age group peers. Embedded in these perceptions and evaluations were questions of the ways older women are portrayed in society, in the media and in the participants' social circles. Although research to abolish the stigma and common stereotypes regarding sexuality, sexual health (Granville & Pregler, 2018) and femininity (Macia et al., 2015) of older women without breast cancer is evident, misconceptions persist that reinforce societal expectations and beliefs (Ylanne, 2015, pp. 374-375). Our findings are consistent with other studies of older women without cancer (Granville & Pregler, 2018; Stahl et al., 2019). Specifically, older women continue to see themselves as sexual

beings that treasure their actions of motherhood, art, music and dancing as sexual expressions (Stahl et al., 2019). Equally important, older women value the emotional intimacy of sexual relationships (Granville & Pregler, 2018).

Outer Processes

Sexuality and femininity for the women of our sample encompassed the desire to freely express themselves through intellectual, physical and behavioral actions. These acts fit prior descriptions of sexuality for older women without cancer, which were not exclusive to sexual intimacy but also included pathways of the sexual energy of art, music and motherhood (Stahl et al., 2019). Our sample was not a homogenous group of women, but varied in their desire for sexual intimacy. One highly educated woman in her seventies apprehensively asked the primary investigator if 80-year-olds have sex. Reflecting on the overall interview and the specific query resulted in pivotal self-reflection and an analytic memo, which illuminated the diversity of sexual interactions with others evidenced across the participants.

Influential factors on the initiation or maintenance of intimate relationships included aging, malignancies such as prostate cancer, the availability of romantic companionship and the effect of chronic illnesses on sexuality has been reported in previous findings (Granville & Pregler, 2018; Schover, 2018; Tetley et al., 2018). Many women who participated in our study also expressed the lack of available male romantic companionship due to cognitive decline, lack of interest in sex, prostate cancer and erectile dysfunction. A few of the women humorously shared stories of men searching for a wife to take care of them, and that the participants were not interested in a relationship of that nature. One woman, who was looking for a committed partner, eloquently expressed this sentiment when she said that she chooses not to be a “mattress, a nurse or a purse.”

Dating after breast cancer was a significant obstacle for a few of the participants. The verbal and physical disclosure of a breast cancer diagnosis to a new intimate partner was a profoundly vulnerable experience for our participants as had been reported in previous findings of a younger (31–68 years) cohort of women with any stage breast cancer (Kurowecki & Fergus, 2014). Similar to our sample of older women, feelings of disfigurement, mutilation, loss of femininity and possible rejection from a new romantic partner warranted caution and a detailed step by step plan in the exposure of the affected breast. It was previously reported that older women were less devastated by the loss of breast tissue than younger women (Kurowecki & Fergus, 2014), and our sample of older women voiced similar sentiment. Yet, lack of devastation did not diminish the heightened concern and hesitation of the exposure of the affected breast to a new romantic partner. Noteworthy of the un-partnered participants in our sample was that none disclosed initiation of a sexually intimate relationship after the diagnosis and treatment of breast cancer.

The women of this study were aware that, as a result of the natural aging process, they were losing the thick hair, smooth skin, firm breasts and the curves that society values. Additionally, breast cancer treatments such as breast surgery, chemotherapy and anti-estrogen therapy posed further specific physical threats to the appearance of their hair and breasts. This confirms the findings that body image concerns and perceptions of loss of attractiveness after breast surgery prevail up to twenty years (Bai et al., 2019). The subsequent fears of rejection, withdrawal and distress that frequently accompanied these self-perception changes impacted the women's lives (Almeida et al., 2012; Boing et al., 2019).

When the participants were asked what constitutes femininity, they described the physical aspects of femininity of enhancing curves, dressing up, wearing jewelry and high heels, looking good and taking care of themselves. Similarly, younger breast cancer

survivors in a recent publication had been shown to outwardly score higher in the manifestation of femininity as a compensatory mechanism to re-establish self-esteem (Jablonski et al., 2018). These intentional actions to express femininity were also found to be characteristic of older women without cancer within the context of aging (Baker & Gringart, 2009), but have not been exclusively studied in an older breast cancer survivor population.

Moving Forward

Clearly demonstrated in our data was that these participants had a unique appraisal of life events. These women described moving past the breast cancer diagnosis and treatment unscathed. The cancer experience was described as a brief segment within their life span. The women incorporated new aspects of sexuality and femininity. Thus, these women evidenced the ability to progress with life, demonstrating resilience and determination to thrive.

Different groups of researchers have found that health care providers were cognizant of the necessity of sexual discussions with cancer survivors and their partners (Jung & Kim, 2016), yet reported that they lacked the knowledge, comfort level (Leonardi-Warren et al., 2016) and time for these conversations to occur (Olsson et al., 2012). Similarly, the women in our study reported the non-existence of sexuality and femininity conversations with physicians, nurses and other health care providers. Furthermore, outside of the clinical setting, sexuality was not discussed with fellow cancer survivors or other women, as one of our study participants spontaneously quipped with an exasperated gasp, “We don’t sit around and have intimate conversations about sexuality.” These women had questions regarding sexuality and femininity yet desired that the health care professionals initiate the discussion of these sensitive topics. In an earlier study, a hindrance to starting these conversations was that the generations of older women were hesitant to initiate conversations about sexual

matters and, instead, relied on clinicians to introduce the topic (Yee, 2010). Similarly, in a recent study with breast cancer survivors, it was also found that the women expected nurses and physicians to broach the subject of intimacy and sexuality (Den Ouden et al., 2019). Conversely, nurses caring for oncology patients reported waiting for oncology survivors to bring up the topic of sexuality (Fitch, 2018). A few of our participants reported answering questions about sexual activity or concerns on an annual health questionnaire, but no follow-up occurred regarding information provided on this questionnaire. Additionally, when a participant's sexual partner inquired about sexual or feminine concerns, the answers received were vague and inadequate. One woman in our study expressed her unhappiness regarding the omission of sexuality conversations as a consequence of the breast cancer diagnosis as an older woman as, "It's really sad, because we are all sexual beings, and just because you have this disease (cancer), it shouldn't mean that that part of your life no longer exists." Prior findings support that sexual activity in older adults remains a high priority to enhance overall well-being (Smith et al., 2019) and maintain a good relationship (Minkin, 2016).

The women of our study echoed the multidimensionality of sexuality and femininity in the enhancement of overall health and well-being. Both of these complex topics were influenced by spiritual, cultural and religious contexts and health-related barriers to sexual activity, sexual thoughts and intimacy. Current research on sexual activity, thoughts and intimacy among older adults is limited (Kolodziejczak et al., 2019), and the investigation of older breast cancer survivors is scarce to non-existent. Research of older adults established that increased age was associated with decreased sexual activity and thoughts, but not with intimacy (Kolodziejczak et al., 2019). The re-establishment of an intimate relationship with an existing or a new partner after a breast cancer diagnosis and treatment in older women has not been exclusively investigated. Previous quantitative research in a sample of younger and older breast cancer survivors

(18-75 years old) three months after breast cancer surgery, revealed that over half of the partnered women reported no sexual activity and no interest in sex (Quintard et al., 2014). However, these researchers can be critiqued for the exclusion of un-partnered women. This investigational premise of sexual activity and libido exclusively in partnered breast cancer survivors assumes access to a readily available intimate sexual partner, but this premise may lead to misrepresentation of sexual activity and desire changes in the larger population of survivors. Furthermore, the disease, potential effects of treatment and the natural aging processes complicate sexual intimacy for older breast cancer survivors (Van Ee et al., 2019). Sexual intimacy additionally is greatly impacted by the overall health of the sexual partner and living environment (Schover, 2017).

Husbands' perspective of their wives' sexual desirability after a mastectomy was found to be critical to their intimate relationship (Hoga et al., 2008). Cultural and religious factors have been found to influence a couples' sexual relationship (Nasiri et al., 2012). A study of Iranian Muslim men showed their preference to not look at their wife's naked body, as seeing the mastectomy scar elicited stress and anxiety along with the suppression of sexual desire for their partner (Nasiri et al., 2012). Findings in a study of Brazilian husbands whose wives had undergone a mastectomy showed they prioritized the preservation of the women's lives, and the breast surgery outcomes did not interfere with the couples' intimate relationships (Hoga et al., 2008). Likewise, five of the ten sexually active participants of our study spontaneously remarked their husbands viewed them as more than breasts. One participant shared a poignant post-mastectomy conversation in which her husband told her, "I didn't marry you for your breasts…I just love you, all of you…it doesn't bother me in the least." Another woman further expressed that while she and her partner were keenly aware that her breasts were "plastic boobs," this knowledge did not interfere with their sexual intimacy.

Beauty as reflected in the eyes of the beholder, the perception of desirability to the significant other, was also vital to the participants of our study. The existence of breast tissue, natural or reconstructed, allowed the majority of the women of this sample to be seen by their sexual partners as whole and sexually pleasing.

The honor and joy of womanhood was expressed in the role of being a wise older woman. This esteemed role of confidante and advisor mirrored the participants' reflection of worth and integrity. Ensuring the preservation and dissemination of essential knowledge of sexuality and femininity exalted their existence within their communities. This finding is consistent with other descriptions that older women commonly empowered themselves in their social communities through mentorship and sharing essential knowledge and wisdom with others (Chrisler et al., 2015, pp. 9-30).

Strengths and Limitations of the Study

To our knowledge this is the first investigation to describe the impact of breast cancer on sexuality and femininity among women aged 65 years and above. Strengths of our novel study include the accrual of a wide age range of older women (65–97 years) at the time of the interview who corroborated that sexuality and femininity remained essential elements in their lives as they grew older and moved beyond cancer. Analysis of the rich descriptive data offered valuable insight into the culturally sensitive topics of sexuality and femininity, which influenced the quality of daily life for this group of older women. The resultant new conceptualization surrounding the intersections of age, chronic illness, relationships, appraisals and misconceptions illuminated our understanding of sexuality, femininity and aging for our sample.

Notwithstanding the aforementioned strengths of the study, there are a number of limitations that should be considered. A key limitation resulted from the difficulty in accrual. The principal investigator had pre-established professional and personal relationships with a large group of oncology health care providers, clinics, cancer and

senior support communities. Despite these associations, an unanticipated barrier to the accrual process was gaining access to potential participants in oncology clinical and community settings. Hence, the results of the investigation reflect a small sample size (N=19). While the 19 interviews generated intriguing and rich descriptions, the criteria and rigor of data saturation were not met as the properties and relationships of the themes and subthemes were not clearly delineated (Charmaz, 2014, p. 214). Hence, the ability to integrate the findings into a theoretical framework and subsequent theory was unattainable (Charmaz, 2014, pp. 192-193).

A second limitation was in regards to the socio-demographic characteristics of the women. The sample demographics regarding socioeconomic status, race, ethnicity, education level and clinical characteristics were quite homogeneous. While the participants were primarily Caucasian, national socio-demographic data indicates a higher incidence of early stage breast cancer in black women aged 65 years and above of 104.2 compared with white females 85.4 per 100,000 women (Howlander et al., 2020). Additionally, all the participants were mothers, heterosexual, highly educated and financially secure residents in Southern California. Thus, a more diverse sample reflecting women of different ethnicities, sexual orientations, socioeconomic and educational status may have offered additional nuanced descriptions of sexuality and femininity.

Potentially related to not reaching saturation, perceptions of the interface of sexuality and femininity before and after the women's experience with cancer were not easily and clearly portrayed. Changes in femininity that followed the breast cancer diagnosis or the treatments were especially hard to tease out, though changes in sexuality may be delineated since it did include re-initiating sexual intimacy. However, sexual intimacy was not always re-initiated because of spousal factors that influenced sexuality for these 19 older women such as the death of a husband, increased

deterioration in cognition and changes in sexual arousal due to prostate cancer or chronic illness. Thus, the limited availability of partners and other losses secondary to natural aging additionally impacted sexuality and femininity and made it challenging to isolate the impact of the cancer specifically.

Self-selection may have increased the likelihood that women who prioritized sexuality and were more engaged in the world responded to the recruitment flyer. Thus, sampling bias may have caused women who read the flyer but opted not to call the researcher would have had an even more difficult time to describe sexuality and femininity than the results reflect.

The cohort effect (Glenn, 2005, pp. 2-4) of shared common world and personal contextual appraisals of marriage, motherhood, widowhood and breast cancer were reflected in the mutual attitudes and behaviors regarding sexuality and femininity of the participants. At the same time, individuals are not solely influenced by world events, common social conventions and portrayals in the media of breast cancer (Black, 1995) during their formative years. Humans act according to the meaning of the situation, reassessing actions, thoughts or notions (Charon, 2010, pp. 114-115). The hazard of oversimplification can occur if we believe exposure to a life event such as cancer, defines the same meaning for every individual in the age cohort.

Another potential limitation is that the principal investigator was a middle-aged female who conducted all the interviews and who was spontaneously described by several participants as being very feminine. Perceptions of feminine embodiment and outward expression of femininity of the principal investigator could have created biases in the participants' responses regarding feminine characteristics, expectations and cultural norms.

Clinical Implications

The main clinical implication of this study is that sexuality and femininity are important for older breast cancer survivors, but discussions on these sensitive topics are lacking in the clinical settings where the sample of this study received care. In my clinical experience, my colleagues know that sexuality and femininity are significant concerns for older breast cancer survivors and their significant others. However, while clinicians may believe that they discussed sexuality despite the awkwardness of such a personal topic, patients and their significant others might disagree. Understanding develops in the presence of new insights, knowledge, clinical evidence and genuine reflection (White, 2012, pp. 4-9). Change takes time. Thirty-five years ago, a review article appeared in the first issue of the oncology nursing professional journal *Seminars in Oncology Nursing* that recommended a sexual history as an essential element of assessment of sexuality for older cancer survivors (Frank-Stromborg, 1985). However, as evidenced by recent research findings and the data of this dissertation, clinicians still have a long way to go to ensure that patients' needs are met.

During their personal interviews, study participants highlighted their unaddressed needs for sexuality discussions. Likewise, in a quantitative study, sexuality for Chinese breast cancer survivors was a neglected issue, with 92% of the women expressing the desire for a professional consultation for sexual issues (Wang et al., 2013). Given these points, breast cancer survivors commonly want and need sexual health care consultation and information. Yet despite this need and desire, our findings indicated that older breast cancer survivors hesitated to initiate sexuality conversations as they waited for health care professionals to bring up the topic. On the other hand, breast cancer survivors were found willing to discuss sexual health concerns when health care professionals initiated the conversations with specific open-ended questions (Canzona et al., 2016). Hence, it is imperative for clinicians to ask specific and open-ended questions (Canzona et al.,

2016) to facilitate the initiation of sexuality conversations with older breast cancer survivors. Furthermore, these conversations for partnered older breast cancer survivors should include discussions of the sexual well-being of their sexual partners.

Prior to their interviews our participants were informed that the topics of sexuality and femininity were the focus of the study. Despite this awareness, they did not initially possess the words to respond to questions about sexuality and femininity. As the interviews progressed, however, the participants were able to express their perceptions and experiences of sexuality and femininity. Thus, a clinical recommendation from this study is that since sexuality and femininity are sensitive topics that are not freely discussed, it will serve patients well if clinicians allow time for women to respond to questions and process the information. Given current time constraints in clinical practice, pragmatic solutions will benefit both clinician and patient.

As an oncology nurse practitioner, a woman in her mid-50s and friend of numerous women that would fit the selection criteria of this dissertation I, too, had previously overlooked the unique needs of women such as those enrolled in the study, during clinical interactions. As a health care professional, I am privy to and astounded by the number of medical charts I have read with ‘deferred’ as the reason gynecological or sexual histories were not assessed in older women. Following this study, I am now more aware than before that, to provide optimal care for older women, the complex interactions of contextual, physical and psychosocial aspects and sexual histories that influence the experience of sexuality and femininity subsequent to early stage breast cancer need to be evaluated.

Documentation of the sexual history (Jung & Kim, 2016) and femininity concerns has the potential to identify needs and acquire appropriate interventions to provide comprehensive care for breast cancers survivors. Specifically, utilization of a geriatric assessment tool such as the Geriatric Sexuality Inventory (Kazer et al., 2013) with older

breast cancer survivors will enhance identification, documentation and conversations of sexual needs and concerns.

Although publications and conference presentations provide frameworks to guide sensitive discussions of sexual function and sexuality (Chism & Goldstein, 2019), health care providers may lack the resources of time (Olsson et al., 2012) and a private space to provide appropriate care. In addition, clinicians may identify the significance of sexuality (Leonardi–Warren et al., 2016) and psychosocial needs of oncologic patients, but they may lack the confidence to manage concerns and symptoms (Olsson et al., 2012; Smith & Baron, 2015). Providers need to maintain a current evidence-based knowledge of sexual health care interventions to strengthen their confidence and ability to provide a proactive and holistic approach to address the needs of oncology survivors (Leonardi-Warren et al., 2016), specifically older breast cancer survivors. Equally important is patient knowledge of and access to educational resources available to older breast cancer survivors and their partners from research groups and organizations such as the American Cancer Society, Cancer and Aging Research Group, National Institute on Aging and breastcancer.org. Additionally, although resources are available, some patients may still necessitate referrals to specialized professionals in gynecology, sexual health, sexology consultation (Streb et al., 2019) and psychosocial support for the women and their sexual partners.

Recommendations for Future Research

Future research should focus on the identification and clinical interventions for fears, perceptions and barriers to sexuality and femininity in older breast cancer survivors regardless of partner status or sexual orientation. Although receiving the diagnosis and treatment were not recalled as shocking by all the participants, a subsample of four women held significant fears of violent imagery and disfigurement. For two of these women the anticipatory fear of the breast cancer treatments equated to

violent acts on the body. The third participant spoke of violent imagery in the anticipated rejection by an intimate sexual partner. The fourth woman spoke of the violent outcome of her bilateral breast tissue reconstruction as a “murder” of her femininity. However, no literature was found about older women with primary breast cancer who had thoughts of violent imagery surrounding the diagnosis or treatments. Thus, based on the preliminary findings about these four women in this qualitative study, future research needs to focus on the presence of these fears and clinical interventions to mitigate them.

Development and testing of a practical guide for health care providers in allotting time, resources and dissemination of information via formats of print, electronic, audio and video for these sensitive topics of sexuality and femininity concerns for older women are needed. Helpful phrases can be identified for the clinical visit such as, “How are things going sexually?” and “Before our next appointment I want you to jot down any thoughts or concerns you or your partner (in case of partnered women) might experience regarding sexuality and femininity and bring the list so we can address any issues.”

Additionally, investigation of the impact of a breast cancer diagnosis and treatment on sexuality and femininity in unpartnered, lesbian, gay, bisexual, transgender and queer individuals is essential to alleviate gaps in current science. Researchers could further study the influence of the “pink ribbon culture of breast cancer” (Thompson & Haydock, 2020, p. 28) on sexuality, masculinity and femininity for cisgender, lesbian, gay, bisexual, transgender and queer women and men.

Future studies of older women who discontinue hormone replacement therapy at the time of breast cancer diagnosis are needed. Side effect management strategies, support interventions and health care providers’ availability to address the meaning and impact of the discontinuation of hormone replacement therapy and initiation of anti-estrogen therapy will add significantly to the limited current body of science.

Disclosure of the breast cancer diagnosis and the physical outcomes of treatment modalities position younger women in a vulnerable situation in the establishment of a new sexually intimate relationship (Kurowecki & Fergus, 2014). However, other cancer survivor communities may also encounter barriers and challenges associated with sexual intimacy and dating after a cancer diagnosis, and this warrants further investigation. Research on dating and sexual intimacy in other cancer survivor communities such as gynecological cancer, lung cancer, colon cancer, hematologic cancer, testicular cancer, prostate cancer, older adults and unpartnered, lesbian, gay, bisexual, transgendered and queer is scarce or non-existent.

Breasts are cultural objects of femininity, eroticism and pleasure (Schlebusch & Van Oers, 2019). Given the current trend that older women are more likely to receive a mastectomy without breast tissue reconstruction (Mays et al., 2017), identification of barriers to the restoration of breast tissue is vital. Breast surgeons are key gatekeepers in the reconstructive process and appear to limit women's choices when all women are not offered a plastic surgery consult (Flitcroft et al., 2019). National statistics of breast surgeon referrals to plastic surgery rates for older women were unattainable. Hence, further research on breast reconstruction options offered to older women requires attention. Investigation is needed on the referral processes, incidences and the barriers encountered by older women.

Conclusion of the Overall Contribution

Sexuality is a vital component of existence for human beings throughout the life span. This study explored the interface of sexuality, femininity and aging within the context of early breast cancer. Our study overall contributes to the body of research on the significance of sexuality and femininity in early stage older breast cancer survivors from their unique perspective. Knowledge generated by this study illuminates the opportunity

for health care providers to explore, understand and address the sexuality and femininity needs of older women after the diagnosis of breast cancer**.**

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Appendix A: Clinical Characteristics (N=19)

Clinical characteristic at date of interview		
Years since diagnosis		
	Mean (range)	9.63 (1-43)
Months since completion of primary treatment		
	Mean (range)	114.68 (6-516)
Primary treatments received (may be more than one)		
	Lumpectomy	11
	Mastectomy	8
	Unilateral total	5
	Unilateral partial	1
	Bilateral total	2
	Radiation therapy	12
	Proton therapy	1
	Chemotherapy	4
Anti-estrogen therapy		
	Aromatase inhibitor	11
	Selective estrogen-receptor modulator	5
	Unsure of name	2
	No anti-estrogen	1
Reconstruction		
	Implant based	
	Unilateral	1
	Bilateral	1
	Autologous	

Appendix B: Study Flyer

FEMININITY AND SEXUALITY AFTER BREAST CANCER

Needed

- Women 65 years and above who finished breast cancer treatment 6 to 36 months ago

What you will do

- Be interview by Melissa Scalia, PhD(c), RN, MSN, AOCNP
- The interview will last about 60 to 90 minutes
- Receive $40 for your participation
- Meet at a mutually agreed upon place of your choice
- Your experiences may help identify overlooked concerns among women who were diagnosed with breast cancer

Please contact
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UCLA

Appendix C: Screening Consent Script

Thank you for calling about the study. I would like to ask you a few questions in order to determine whether you may be eligible for the research. Before I begin the screening, I would like to tell you a little bit about the research. The proposed study is to understand the experiences, perceptions, beliefs and processes of defining femininity and sexuality in women 65 years or above after the diagnosis of breast cancer and treatment.

Would you like to continue with the screening? The screening will take about fifteen minutes. I will ask you about the breast cancer diagnosis and treatment, your age, willingness and ability to share your story in English. You do not have to answer any questions you do not wish to answer or are uncomfortable answering, and you may stop at any time. Your answers will be confidential. No one will know your answers except for the research team. If you do not qualify or decide not to participate in the research study the research team will shred the screening questionnaire to destroy all of your personal information collected during the screening process. If you qualify for the research study and decide to participate all information will be kept in a secure location. At the conclusion of the study all screening documents will be shredded to maintain your privacy, anonymity and confidentiality.

Would you like to continue with the screening? [If 'no', thank the person and hang-up]
[If 'yes', continue with the screening]

1) Have you been diagnosed with breast cancer?
   yes_____ no_____ (ineligible for study thank the person, explain and hang up)
2) Have you received treatment for breast cancer (last received)?
   yes_____ no_____
3) Dates of primary treatment(s) for breast cancer? (less than 6 and more than 36 ineligible)
   Surgery: month_____ year_____
   Chemotherapy: month_____ year_____
   Radiation therapy: month_____ year_____
   Have you received any chemotherapy, surgery or radiation therapy in the last six (6) months?
   yes_____ (ineligible for study, thank person, explain and hang up) no_____
4) What is your date of birth? _____
   (less than 65 years of age ineligible thank person, explain and hang up)
5) Have you ever been told you have another type of cancer?
   yes _____ what type?_____ (non-melanoma still eligible) no_____
6) Would you be willing to share your story regarding the cancer diagnosis and treatment?
   yes_____ no_____ (ineligible thank person, explain and hang up)

Thank you for answering the screening questions. You are eligible for the study.
Do you have any questions about the screening or the research? I am going to give you a couple of telephone numbers to call if you have any questions later. Do you have a pen? If you have questions about the research screening, you may call (name of dissertation chair and number) If you have questions about your rights as a research subject or if you wish to voice any problems or concerns you may have about the study to someone other than the researchers, please call the UCLA Office of the Human Research Protection Program at (310) 825-7122.
Thank you again for your willingness to answer our questions.

Appendix D: Dr. Huibrie Pieters' Invitation Script

Re-introduce self: Good morning/afternoon, this is Dr Huibrie Pieters from the UCLA School of Nursing. We met to discuss your experiences about the medication that you are on/had stopped (whatever applies to the woman).

Checking in with the participant: How are things going since we last spoke? When we spoke, you said I was welcome to contact you to invite you to participate in future studies. This is the purpose of my call today.

Invitation/contact request: Would it be acceptable for a doctoral student who is also a nurse, to call and invite you to participate in her study? The aim of her study is to understand the experiences that surround femininity and sexuality after treatment for breast cancer. Please do not feel obligated to participate or answer 'yes'.

Do you have any questions for me at this time?

Verifying participation: May the doctoral student contact you?
(If 'no', thank the person and hang-up)
(If 'yes', continue with invitation script)

Is this the best phone number for the doctoral student, Melissa Scalia, to contact you?
Phone number to contact potential participant: (626) 241- 2400
Is there a day of the week and time that is best for Melissa to contact you?
May Melissa leave a message at this phone number?
Yes/ no

Thank you for your availability and willingness to potentially participate in the study.

Appendix E: Socio-demographic Characteristics (N=19)

Characteristic		
Age at interview		
	Mean (range)	77 (65-97)
Self-identified race or ethnicity		
	Caucasian	16
	Asian	1
	African American	1
	Latina	1
Marital status		
	Widowed	11
	Married	8
Highest completed education		
	High school	1
	Some college	5
	Associate degree	2
	Bachelor's degree	1
	Some graduate school	1
	Master's degree	8
	Doctorate	1
Annual household income		
	Comfortable, more than enough	11
	Enough to make ends meet	8
Employment status		
	Gainfully employed	1
	Retired	18
Living situation		
	Retirement community	
	Independent living	4
	Assisted living	2
	Suburban community residence	
	Single family home	11
	Condominium	2
Place of interview		
	Single family home	8
	Independent living	4
	Assisted living	2
	Senior center	2
	Cancer support center	2
	Café	1

Appendix F: Demographic and Clinical Treatment Questionnaire

Ethnicity:
Date of birth:
Date of diagnosis:
Living environment: house/ apartment/ community retirement community/ assisted living
Currently in sexually active or romantic relationship: yes/ no
Partner status: no partner/ stable partner/ occasional partner
Menopausal status at diagnosis: menopausal/ pre-menopausal
Current menopausal status: menses (monthly period) yes/ no
Employment status: Gainfully employed: yes/ no
Annual household income:
Considering the amount of money that comes into the household for you to live on, would you say, you:

Are comfortable, have more than enough to make ends meet.
Have enough to make ends meet.
Do not have enough to make ends meet.

Breast cancer surgery information:

Date:
Type:
Reconstruction: yes/ no

Treatment trajectory: dates received

Chemotherapy: Radiation therapy:

Anti-estrogen therapy: yes/ no
Start date of anti-estrogen therapy:
Highest level of education completed:
Please tell me about your general health in one sentence:
Do you have any of the following symptoms?

a. Shortness of breath: yes/ no
b. Fatigue/tiredness: yes/ no
c. Swelling in the legs: yes/ no
d. Do you use extra pillows at night to sleep because you are short of breath? yes/ no
e. Diabetes: yes/ no
f. High blood pressure: yes/ no
g. Urinary incontinence/loss of urine: yes/ no
h. Arthritis: yes/ no

Are you on any of the following medications?

Tamoxifen: yes/ no
Letrozole (Femara): yes/ no
Exemestane (Aromasin): yes/ no
Anastrozole (Arimidex): yes/ no

Any changes to your medications in the last 6 months? yes/ no

Appendix G: Semi-Structured Interview Guide

Introduction

Thank you for agreeing to participate in this conversation. I want to remind you I am here to learn about your individual experiences surrounding the breast cancer and treatment so it is very important for you to know there are no right or wrong answers. Every person is unique. Also, if you do not want to answer a question it is perfectly all right. Also, you may find that at times I will return to questions we have discussed before. That does not mean you did not answer the questions correctly. It just means we are revisiting the ideas to help me understand them better. Do you have any questions? (If 'no') I will switch the recorders on now.

Topic	Question	Prompt
Breast Cancer	Is there anything about the breast cancer diagnosis that stands out for you?	What was treatment like for you?
	Now let's focus on the time right after diagnosis and treatment, is there anything that stands out about that time?	
	Some women report feeling different and others not so much after the breast cancer diagnosis and treatment. Please share your experience.	Please tell me what has life been like after the breast cancer diagnosis and treatment?
Femininity: being a girl	Now, let's talk about growing up being a girl. Please tell me your background.	How, where and with whom did you grow up?
	Looking back when you were a young girl what stands out to you?	
	What was the most important thing about being a girl at that stage of life?	
	How did that contrast with the young boys you knew?	
	What advice did you receive about being a girl?	Please share some everyday examples.
	What advice or coaching did you receive about being a girl?	
	Sometimes when girls are growing up, they receive do and do not's for girls. What was your experience?	What can you remember seeing or encountering about rules or behaviors for girls?

Femininity: teenage girl	Now let's talk about being a teenage girl. What kind of expectations did you see for teenage girls growing up?	What in the media or society did you see about being a teenage girl?
	How does that contrast to boys the same age group of teenagers?	
Femininity: becoming a woman	Now let's talk about becoming a woman. Looking back as a teenage girl when you realized you were now a woman and no longer a girl?	What was the event, everyday example or incident? How did you feel?
Femininity: being a woman	Looking back, when was the first time you remember feeling like a woman?	Please give me an everyday example.
	How would you describe femininity?	What comes to your mind when I say femininity?
	What does femininity mean to you?	
	How does a woman express femininity?	Can you give me some everyday examples?
	In your opinion, does femininity differ across countries and cultures?	
	What does it mean to be feminine in our culture? How do you see femininity and being a woman?	Are they connected, please share some everyday examples?
	How do you see femininity in yourself?	Please share how others view femininity in you.
Being a woman, femininity and the diagnosis of breast cancer	Now let's move our discussion about being a woman and femininity to include the diagnosis of breast cancer. Some women note changes in how they view themselves as a woman after breast cancer and treatment. Please share with me your experience.	Think back to the time of the diagnosis and treatment, what were your thoughts about your femininity?
	Looking back, since the diagnosis and treatment of breast cancer what has been the most important thing to you regarding femininity?	

	Has anyone spoken to you about any femininity concerns a woman like yourself may encounter after the diagnosis and or treatment?	
	Is there any concern you may have encountered concerning femininity after the breast cancer diagnosis and treatment that you wish someone would have explored with you?	Can you think of an everyday example of something about your femininity you would have wanted to discuss with someone but did not?
Sexuality	Thank you very much for sharing about femininity. Now I want our discussion today to move to sexuality. What comes to mind when I say sexuality?	What is sexuality to you?
	Now, please think about any concerns a woman like you may have encountered regarding sexuality after the breast cancer diagnosis and treatment. Please share your experience.	
	Some women report a desire to be in a romantic and or sexual relationship after the cancer diagnosis and treatment. Please share your thoughts?	
	Please share with me the place sexuality has in life?	Can you think of an everyday example of sexuality that you see in your life?
	What comes to mind when I say sexual health?	
	How does a woman maintain sexual health throughout her life?	Please share an everyday example of sexual health maintenance.
Aging	Advancing age is a concern to some individuals but less so to others; please share your thoughts.	
	When I say women 65 years or older what image comes to mind?	Please describe the image.
	Now picture a woman 65 years or older with breast cancer what comes to mind?	Does the image look the same as the previous one?

Aging and the diagnosis of breast cancer	Now think about any concerns you as an individual may have encountered regarding advancing age after the diagnosis of breast cancer. Please share your experience.	Can you think of worries that you may have had about being older when you were diagnosed?
	Is there anything that you expected your health care team could have asked you to explore your concerns or needs?	Please share with me some things they could have discussed with you about your needs.

Closing the interview

Our discussion today is about to end. At this time is there anything else we have not discussed that you feel would be important to share? Is there anything that you expected I would ask you to explore and that I have not asked?
Thank you very much. I will now switch off the recorders.

Appendix H: Themes and Subthemes of Older Women's Reflections on Experiencing Sexuality and Describing Femininity Following Early Stage Breast Cancer

	Receiving the Diagnosis	Experiencing Sexuality	Describing Femininity
Inner Processes	Shock Violent imagery and disfigurement Fear of consequences Suffering and gratitude	Proceeding with limited education and naiveté Navigating around the taboos Societal values Giving limited education	Ethereal dimensions Education Elusive Beauty from the inside Masculinity and femininity as complementary Intentionality Threat to femininity
Outer Processes	Disclosure Support from others Suffering of self and others Seeking knowledge Speaking up	Learning by doing Multidimensional facets Coitus–sexual intercourse Diversity of lived experiences	Threat to femininity Unmasked Pre-existing barriers Societal expressions of femininity Changing gender roles over time Cultural stereotypes Transition into womanhood
Moving Forward	Cancer happens Moving from thoughts of death back to thinking about life Moving past the diagnosis Putting cancer in its place	Physical changes Anti-hormonal treatment Intimate encounters Planning for intimacy Pornography Beauty in the eyes of significant other Sexuality without a sexually intimate partner Wise sex educator	Emotional support after the diagnosis Emotional outcomes of reconstructive surgery Sexuality and femininity discussions with health care providers Appraisal and preservation of femininity Role of wise older woman Persistent thoughts of death