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# Sex and Sexuality of Breast Cancer Survivors

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# SEX AND SEXUALITY OF BREAST CANCER SURVIVORS

by

Aja D. Kneip Pelster

A Dissertation

Presented to the Faculty of  
The University of Nebraska Graduate College  
In Partial Fulfillment of the Requirements  
For the Degree of Doctor of Philosophy

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Under the Supervision of Professors  
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## Table of Contents

Acknowledgements.....	i
Table of Contents .....	ii
Abstract.....	v
<b>CHAPTER 1: Introduction .....</b>	<b>1</b>
Global Cancer Burden .....	1
Breast Cancer.....	2
Quality of Life .....	4
<i>Table 1</i> .....	5
Survivorship.....	7
Conclusion.....	10
Statement of Purpose.....	11
<b>CHAPTER 2: Literature Review .....</b>	<b>12</b>
Introduction .....	12
<i>Women's Breasts in US Cultural History</i> .....	14
<i>Breast Cancer in US Cultural History</i> .....	18
<i>Sexual Script Theory</i> .....	20
<i>Biomedical Script in the Literature</i> .....	26
<i>Relational Script in the Literature</i> .....	28
<i>The Missing Script in the Literature: The Survivorship Script</i> .....	29
Conclusion.....	31
<b>CHAPTER 3: Methods.....</b>	<b>34</b>
Qualitative Research Methods .....	34
Narrative Research .....	34
Phenomenological Research.....	35
Bracketing: The Role of the Researcher in Qualitative Inquiry .....	36

Study Population and Recruitment.....	38
Study Design .....	39
Procedures.....	42
Analysis.....	44
<b>CHAPTER 4: Sexuality, Breast Cancer Survivorship &amp; Script Theory .....</b>	<b>46</b>
<i>Abstract</i> .....	46
Introduction .....	46
<i>Survivorship Defined</i> .....	48
<i>Introduction to Script Theory</i> .....	48
<i>Statement of the problem and research question</i> .....	51
Methods .....	52
<i>Table 2</i> .....	54
<i>Participant Description (N=21)</i> .....	54
<i>Table 3</i> .....	56
<i>Semi-Structured Interview Format</i> .....	56
Results .....	56
<i>Introduction</i> .....	56
<i>The Caregiver Script</i> .....	56
<i>The Scripts of Loss</i> .....	58
<i>Script of Survival</i> .....	61
Discussion .....	64
<i>Limitations</i> .....	67
Conclusion.....	68
<b>Chapter 5: To Whom Belongs the Breast: a qualitative exploration of the complicated role of breasts after breast cancer .....</b>	<b>69</b>
<i>Abstract</i> .....	69

Introduction .....	69
Literature Review .....	71
<i>Women’s Breasts in US Cultural History</i> .....	71
<i>Breast Cancer in US Cultural History</i> .....	75
Methods .....	77
<i>Qualitative Research Methods</i> .....	77
<i>Study Population and Recruitment</i> .....	78
<i>Procedures</i> .....	80
<i>Analysis</i> .....	81
Findings.....	82
<i>Societal Influences on the Breast</i> .....	82
<i>Interpersonal Influences on the Breast</i> .....	83
<i>Internal Influences on the Breast</i> .....	86
Conclusion.....	87
<i>Limitations</i> .....	90
<b>CHAPTER 6: Reflections from an Insider Researcher .....</b>	<b>91</b>
Introduction .....	91
Insider or Outsider? That is the Question .....	96
Importance of the Survivorship Timeline .....	98
The Fundamental Role of Personal Lenses, Assumptions, and Biases .....	99
Conclusion.....	101
<b>APPENDIX.....</b>	<b>104</b>
Appendix A: Interview Guide – Sexual Satisfaction and Survivorship .....	105
<b>REFERENCES .....</b>	<b>108</b>

# SEX AND SEXUALITY OF BREAST CANCER SURVIVORS

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## Abstract

With new diagnostic technologies and treatment modalities available, more people than ever are living as cancer survivors in the United States. A large group of this population consists of breast cancer survivors. The purpose of this research was to explore the intersection of breast cancer survivorship, at points beyond the termination of treatment, and sexuality, including expressions and performance of gender, relationships, and sexual behavior. The current study used semi-structured interviews, conducted with 21 Midwestern women at least 6-months post-treatment, to better understand the intersection of these two concepts. Following traditions of narrative and phenomenological qualitative research, the women's own stories were used to explore the impact that survivorship, diagnosis, and treatment may have on a woman's sexual self. Results are presented through manuscripts exploring the role of sexual script theory and the role of the breast in the lives of women after breast cancer. This study found that women's sexual scripts were impacted by a diagnosis of breast cancer. For participants of this study, new scripts emerged that assisted in making meaning of the experience.

## **CHAPTER 1: Introduction**

### **Global Cancer Burden**

The extreme severity of the global cancer burden has left few individuals untouched. Whether one is the recipient of a diagnosis, a caregiver, or even an acquaintance, there is difficulty in finding individuals who have not been directly or indirectly impacted by cancer. The World Health Organization (WHO) estimates that within the next 20 years the number of new cancer cases will increase by nearly 70%, from 14 million in 2014 to nearly 22 million new diagnoses each year (2014). Of the 14 million new diagnoses that occurred throughout the world in 2014, over 1.6 million new diagnoses occurred within the United States. Estimates are that 40% of Americans will be diagnosed with cancer at some point in their lifetimes (Howlander, Noone, Krapcho, 2014). According to American Cancer Society estimates, this rate is equivalent to one in three women or one in two men developing cancer in their lifetimes (2014).

Cancer is a classification of over 100 different diseases in which there is an uncontrolled division of abnormal cells resulting in the body's tissues, systems, and organs to be compromised. Each type of cancer has its own risk factors, treatment, survival rates, and burden imposed upon the community within which that specific cancer is found. Globally, the highest incidence of cancer for men comes from cancers of the prostate (1.4 million diagnoses), while for women that classification goes to breast cancer (1.8 million diagnoses) (Global Burden of Disease Cancer Collaboration, 2015).



In the United States, even as recently as the 1990s, the increase in the incidence of cancer was accompanied by an increase in mortality associated with the disease (Jemal et al., 2008). By 1991, the mortality rate associated with all cancers was 215.1 deaths per 100,000 individuals in the population. This rate has since begun to diminish. In recent decades even as rates of new diagnoses have steadily increased, mortality rates associated with cancer have decreased (Jemal et al., 2008). By 2010, the rate of mortality associated with all cancers was 171.8 per 100,000, a 20% decline from 1991 (Siegel, Ma, Zhou, & Jemal, 2014). A great deal of cancer death comes from cancers associated with smoking behaviors. The risk factor of smoking is associated with tracheal, bronchial, and lung cancers. These three cancers constitute the leading cause of cancer death in the world (1.6 million deaths) (Global Burden of Disease Cancer Collaboration, 2015).

### **Breast Cancer**

Similar to global incidence, breast cancer is the most common cancer experienced by women in the United States. According to the Centers for Disease Control and Prevention, this commonality is true regardless of race or ethnicity (2014). Breast cancer was estimated to account for 14% of all new cancer diagnoses in 2015 (CDC, 2014). Roughly 1 in 8 women, or 12.3% of women in the United States will be diagnosed with the disease in their lifetime (DeSantis, Ma, Bryan, Jemal, 2013; CDC, 2014). In 2012, the population of women who had been diagnosed with breast cancer in their lifetime in the United States consisted of nearly three million women (Howlader, Noone, & Krapcho, 2014). Breast cancer is the third leading cause of cancer death in the United States

surpassed only by pulmonary and colorectal cancers (Howlader, Noone, & Krapcho, 2014).

Similar to all cancer rates in the U.S., the decline in mortality associated with cancer has also been true of breast cancer. In 2000, the United States saw a 25% decrease in breast cancer death in women 20-69 years of age as compared to peak mortality years for that same group in the 1990s (Peto, Boreham, Clarke, Davies, & Beral, 2000). By 2010 that rate had decreased by 34% as compared to 1991, with the greatest decline seen for those women diagnosed prior to the age of 50 (DeSantis, Ma, Bryan, & Jemal, 2014).

There are many factors that may put an individual at higher risk for a breast cancer diagnosis. Un-modifiable risk factors for breast cancer are those risk factors that the individual cannot change. These factors include a woman's age, age at menarche and menopause, history of previous breast disease, and family history. As a woman's age increases, so does her risk of developing breast cancer. Women who experience early menarche or late menopause are also at increased risk for the disease (McPherson, Steel, & Dixon, 2000).

Some risk factors for breast cancer may be modifiable. Modifiable risk factors include those risk factors that the individual may have some power to change. Modifiable risk factors for breast cancer are largely the lifestyle characteristics and the behaviors of that individual. These include diet, weight, use of oral contraceptives, and the use of alcohol and tobacco (McPherson, Steel, & Dixon, 2000). For women who have chosen to use oral contraceptives, the risk of breast cancer is slightly increased during the use of

this class of drug, but this effect is lost after discontinuing the use of the drug for ten years (McPherson, Steel, & Dixon, 2000).

### **Quality of Life**

More people today than ever before are living longer after an initial diagnosis of cancer due to advancements in medical technologies in cancer treatment and detection (Barton-Burke & Gustason, 2007; Siegel et al., 2014; DeSantis, Ma, Bryan, & Jemal, 2014). Survivors also live with the possible aftermath of cancer and its treatment. These advancements have created an opportunity for a shift in emphasis from individual survival to a person's quality of the life in the face of the disease. As the population of people directly impacted by cancer continues to grow, new ideas surrounding living with and loving one's body after a cancer diagnosis will continue to become increasingly important.

Treatment options for cancer are closely related to the quality of life of oncological patients. Each treatment option brings with it specific threats to the person's quality of life. Each type of cancer has distinctive treatment options. These options are available for region specific cancers (i.e. treatments for prostate cancer as compared to lung cancer), as well as within specific regions (i.e. hormonal breast cancers as compared to a triple negative breast cancer diagnoses). Each stage of diagnosis and tumor characteristic requires a different type of treatment. Although there are many ways that breast cancer can be treated, this study examined the impact on quality of life of four of the most common forms of treatment: surgery, chemotherapy, radiation, and hormone therapy. Depending on the individual and specific tumor characteristics, these treatments

may be used alone or may work as compliments to one another. Each treatment brings with it risks to quality of life and impacts on the various dimensions of health, whether that be physical, mental, emotional, or social impacts. (See Table 1 for comprehensive list of threats to QOL).

**Table 1**

Common Breast Cancer Treatments and their Impact of QOL

Treatment	Immediate Side Effects	Short-Term Impacts	Long-Term Impacts
<b>Surgery</b>	Bleeding <sup>1</sup> Tissue Damage <sup>1</sup> Adverse Drug Reactions <sup>1</sup>	Pain <sup>1</sup> Infection <sup>1</sup> Blood Clots <sup>1</sup> Lymphedema <sup>5</sup> Numbness <sup>5</sup> Tightening of Shoulder <sup>2,5</sup> , Arm <sup>5</sup> , and Chest wall <sup>5</sup>	Pain <sup>1</sup> Decreased Range of Motion <sup>1</sup> Lymphedema <sup>5</sup> Numbness <sup>5</sup> Tightening of Shoulder <sup>2,5</sup> , Arm <sup>5</sup> , and Chest wall <sup>5</sup>
<b>Radiation</b>	Fatigue <sup>1,2</sup> Swelling <sup>1,2</sup> Skin Irritation and Burns <sup>1,2</sup>	Swelling <sup>2</sup> Blood Clots <sup>2</sup> Numbness <sup>5</sup> Tightening of Shoulder <sup>2,5</sup> , Arm <sup>5</sup> , and Chest wall <sup>5</sup> Radiation Pneumonitis <sup>1</sup> Prohibited from Wearing a Bra <sup>1</sup> Prohibited from Wearing Deodorant, Lotions, Creams <sup>1</sup>	Additional Cancers <sup>2</sup> Numbness <sup>5</sup> Tightening of Shoulder <sup>2,5</sup> , Arm <sup>5</sup> , and Chest wall <sup>5</sup>
<b>Chemotherapy</b>	Fatigue <sup>2</sup> Nausea <sup>2</sup> Vomiting <sup>2</sup> Anxiety <sup>2</sup> Hair Loss <sup>1,2</sup>	Cancer Related Brain Fog <sup>2</sup> Hot Flashes <sup>2</sup> Sudden Menopause <sup>2,5</sup> or Amenorrhea <sup>3</sup>	Hot Flashes <sup>2</sup> Nerve Damage <sup>2</sup> Additional Cancers <sup>1</sup> Infertility <sup>1,5</sup> Cardiovascular Damage <sup>1</sup> Nerve Damage <sup>1</sup> Organ Damage <sup>1</sup>
<b>Hormonal Treatment</b>	Diarrhea <sup>2</sup>	Muscle Aches and Pains <sup>2,5</sup> Hot Flashes <sup>2</sup> Osteoporosis <sup>5</sup>	Muscle Aches and Pains <sup>2,5</sup> Hot Flashes <sup>2</sup> Osteoporosis <sup>5</sup>

<sup>1</sup>(American Cancer Society, 2016)<sup>2</sup>(Boston Women's Health Book Collective, 2005)<sup>3</sup>(Charif et al, 2015)<sup>4</sup>(Love et al, 1992)<sup>5</sup>(Siegel et al, 2012)

Many treatment plans for breast cancer patients include some type of chest surgery. In the past, treatment with surgery has ranged from a removal of the tumor and some breast tissue to more radical surgeries that remove the breast and at times a part of the chest wall (Boston Women's Health Book Collective, 2005). Presently, tissue-saving surgeries, such as lumpectomies, have become more common and accepted as surgical techniques to remove breast cancer tumors (Kelly, 2008). Chest surgery for the treatment of breast cancer can result in consequences related to quality of life. These consequences may be short- or long-term and might include impact on body image, range of motion and motility of the arm, pain, and life-long management of edema (Nowicki, Licznerska, & Rhone, 2015).

Many breast cancer patients are also prescribed a chemotherapy regime. This treatment is used to destroy microscopic cancer cells that may exist in the body even after surgical removal of the tumor. With chemotherapy, depending on the drug cocktail, side effects may include nausea, hair loss, neuropathy, premature menopause, or fatigue (American Cancer Society, 2016; Boston Women's Health Book Collective, 2005).

Radiation is also a common form of treatment after a diagnosis with breast cancer. While chemotherapy uses the body's circulatory system to go to all parts of the body to find and eliminate cancer cells, radiation is used to destroy cancer cells that may persist at the tumor site after the tumor has been removed and circulation to that site is changed. Impacts on quality of life due to radiation may include thickening or thinning of the skin, pain, or sensitivity (American Cancer Society, 2016).

Finally, hormone therapies are used when the cells of the tumor have estrogen receptors. This class of drug blocks these receptors and causes the tumor to stop growing or to shrink. Patients who undergo hormonal therapies often do so for extended periods of time after the original diagnoses. Some of the many side effects associated with hormonal therapies include fatigue, body aches, hot flashes, and decreased bone density (Boston Women's Health Book Collective, 2005).

In addition to these specific threats to quality of life that are characteristic of each treatment, there may also be more generalized risks associated with the original diagnosis outside of the treatment provided. These may include fear of reoccurrence, anxiety, mood disorder, or depression (Massie, 2004). Risks for these outcomes are increased in women who have been diagnosed prior to the age of 50 (Ahmad, Fergus, & McCarthy, 2015). In fact, cancer survivors are over two times more likely to experience psychological disability than their disease-free counterparts (Hewitt, Rowland, & Yancik, 2003).

### **Survivorship**

Using the term first coined by Dr. Fitzhugh Mullan (1985), survivor refers to any person who has been diagnosed with cancer, initiating at the point of diagnosis. Through his work and his own experience with the disease, Dr. Mullan noted that the terminology that was normally associated with disease did not appropriately describe life after diagnosis and treatment of cancer. He saw that standard treatments for cancer often allowed for the hope of longer lives and potentially survival, but with the use of these treatments further complications, from annoyances to lethality, could and did occur

during treatment and for many years afterwards (Aziz & Rowland, 2003). Whether due to the effects of treatment or diagnosis, emotional and physical changes needed to be made after an initial introduction to the disease. For researchers like Dr. Mullen (1985), something happened when a person was diagnosed with cancer, and the population of people who had been diagnosed with cancer shared fundamental experiences that set them apart from the rest of the population. These experiences did not require short-term changes, but long-term adjustments that followed that person throughout their lifetime. Because of the lifetime impact of treatment and possible lifetime adherence to treatment, simple binaries, such as cured/not cured or healthy/diseased, no longer applied.

The designation of survivor comes at the point of diagnosis and follows that individual throughout their lifetime (Mullan, 1985). The definition set forth by the U.S. Centers for Disease Control and Prevention (CDC) agrees, but has gone farther by defining survivors as people who have lived with, through, or beyond cancer and recognizes the far-reaching impact of cancer by including family, friends, and caregivers within its description.

According to the CDC, the population of people who can identify themselves as survivors in the U.S. has grown nearly threefold in the last 40 years. As of 2007, 11.7 million people were living after having been diagnosed with cancer. The prevalence of survivors in the US is up from 9.8 million in 2001 and a mere 3 million in 1971 (2010). The American Cancer Society estimates that there were 1,638,910 new cases of cancer and 577,190 deaths from the disease in 2012. Over a lifetime, these statistics translate to

one in every two men and one in every three women experiencing an invasive cancer diagnosis thus becoming a survivor (CDC, 2014). For women, estimates for newly identified survivors (diagnoses) are expected largely from breast cancer, the most common invasive cancer in women (29% of reported cancers) (Siegl, Naishadham, & Jemal, 2012).

Beyond survival from the disease, cancer touches all aspects of survivor's life including the mental, social, emotional, and sexual dimensions of overall health and well-being. Consequences of cancer and its treatment range from the highly individualized, such as pain and mental distress, to interpersonal and social issues, such as adjustments within relationships and issues in being able to continue caring for families or working (see table 1).

At times these layers of impact on a person's health are overlooked or missed by healthcare professionals. Lack of communication about the impact of cancer and treatment is especially true when sexual health is considered. One study with ovarian cancer survivors found that 25% of physicians and only 19% of nurses discussed sexual issues with the women who had been diagnosed, despite knowing that a majority of women with ovarian cancer would experience difficulties associated with sex (Stead, Brown, Fallowfield, & Selby, 2003). Embarrassment, lack of knowledge about sex, and a perception that responsibility to bring up sexual issues lies with the patient, have all been sighted as reasons that healthcare providers give for not broaching the subject of sex (Sacerdoti, Lagana' & Koopman, 2010). An additional study in France found that less than 50% of women were satisfied with the amount of fertility- and sexuality-related



information shared with them by health care providers after their diagnosis (Charif et al., 2015).

Across one's lifespan, sex, sexuality, and how an individual expresses their gender is important. Consideration of these factors may even be more important after a diagnosis of cancer. These missed opportunities for discussion with patients may mean missed opportunity for intervention (Barton-Burke & Gustason, 2007). The importance of sex, sexuality, and gender expression may be especially true in the case of breast cancer, specifically, due to the location of the cancer and the involvement of the breast. The historical and societal landscape of the United States positions the breast firmly within the domains of femininity (Haiken, 1997), sex and sexuality (Yalom, 1997) in our culture.

## **Conclusion**

The global burden of cancer is high and continues to increase. Breast cancer is the most commonly experienced cancer diagnosis among women globally and in the United States. Survivorship encompasses the individual experience of diagnosis and treatment, but the influence of survivorship on a woman's life persists well beyond this point. The impact has wide-ranging and often severe consequences for all individuals in the survivor circle, including less often discussed topics of sex, sexuality, and gender expression. Much work remains to be done to understand the experiences of survivors and the impacts of survivorship on sex, sexuality, and gender expression.

## **Statement of Purpose**

The overall purpose of this qualitative study was to explore how women navigate sex, sexuality, and sexual intercourse after diagnosis and treatment of breast cancer.

Qualitative interviews with women breast cancer survivors were conducted to better understand with phenomenon through the narratives of participants. This study proposed to accomplish the following aims:

- Aim 1:** Explore the impact of cancer diagnosis and treatment on the sexual scripts of women who had been diagnosed and treated for breast cancer throughout their survivorship (lifetime).
- Aim 2:** Identify characteristics unique to breast cancer survivor's cultural, interpersonal, and intrapsychic sexual scripts.
- Aim 3:** Explore physical and emotional adaptations that women make after diagnosis and treatment of cancer.
- Aim 4:** Determine if survivorship milestones (i.e. completion of treatment, the one-year anniversary of diagnosis) have an impact on the sexual scripts of women who have been diagnosed or treated for breast cancer.

## CHAPTER 2: Literature Review

### Introduction

Anyone with breast tissue has the risk factor necessary to develop breast cancer. However, women experience a disproportionate share of this disease. Men account for less than one percent of breast cancer diagnoses (Quincey, Williamson, & Winstanley, 2016). Conversely, one in eight women will be diagnosed with breast cancer in their lifetime (American Cancer Society, 2015). This disproportionate representation among women has led to a gendering of the disease. Prevention efforts are saturated in the color pink while awareness campaigns focus on the loss of the breast as an assault against the female form. Evidence of this association between breast cancer and the feminine body are plentiful within U.S. society.

Many breast cancer awareness and prevention campaigns are focused through the lens of heterosexism. One common example of this heterosexism is the association of breast cancer with the pink ribbon and color pink broadly (Zavestoski, McCormick, & Brown, 2004). American consumers can find nearly any product pink-washed; there are pink foods, pink office supplies, pink pepper spray, even a pink cement mixer (Ryan, 2012). During the month of October, also known as National Breast Cancer Awareness Month, in cities like Philadelphia or Kansas City the fountains spurt pink water. These popular breast cancer awareness campaigns rarely center on the individual who has been diagnosed with the disease, but rely on the social construct of the sexualized breast (Zavestoski, McCormick, & Brown, 2004). T-Shirts and posters support this idea with slogans like “Save Second Base” or “I Stare Because I Care”. These types campaigns move the discussion away

from the prevention of cancer as being a threat to a woman's well-being or quality of life, and focus the discussion on the threat to pleasure that another may be denied. In these examples, the impact of breast cancer on the woman who is diagnosed is not a priority. The impact that this gendered lens may have on the woman who is diagnosed is absent.

The diagnosis and treatment of breast cancer for most women includes at least one surgery wherein breast tissue is removed. The amount of tissue removed is dependent on several factors including diagnosis and prognosis, recommendations of clinicians and surgeons, and individual characteristics of the patient. This invasive and possibly traumatic experience forces women to assess their relationship to their breasts. Although some research has explored the experiences of women after a diagnosis of breast cancer, a gap exists regarding the impact that the perceived meaning of the breasts have for women, partners, and society after a diagnosis of cancer. Current trends in how the female breast is situated within society and the many ways in which society and other individuals exact ownership over the female breast during disease are important to a comprehensive understanding of the social and cultural role of the female breast.

These trends in how the breast is perceived and positioned within society are important because one's sexuality and embodiment of gender is informed by the society, religion, and culture in which one lives. Perceptions and interpretations of the breast are constructed from the social and cultural environment. In the Western culture, that social and cultural environment has created many different versions of the female breast throughout history. These perceptions are not concepts entirely external to the individual, but are also embodied by that individual. In effect, the perception of one's own body

comes not only from the self but also from these external influences. To understand individual interpretation of the breast, one must understand cultural and societal interpretation. To understand the societal and cultural perception of breasts, breast cancer, and treatment that breast cancer plays, one needs to understand the history of the breast and the role that the breast has played and continues to play in Western society and culture.

### **Women's Breasts in US Cultural History**

There are many roles that the female breast fills. The breast can be seen as a source of sustenance for young, an erotic and pleasurable organ, or even a source of power. Theories on the biological and reproductive purposes of breasts come from evolutionary biology and psychology. Within these fields the breast, beyond an organ for nursing offspring, is seen as a mirror of the posterior and an evolutionarily selected trait that allowed prehistoric women to draw attention to the front of the body as humans began to walk upright and engage face-to-face in sexual intercourse (Barber, 1995; Ryan & Jethá, 2010). While these may be the evolutionary beginning for the human breast, these beginnings by no means constitute the comprehensive story of the current role of the breast in the lives of individuals and society.

Historian Marilyn Yalom (1997) created a social timeline of eight distinct conceptions of the human breast in Western thought, particularly American and European thought. These conceptions of the breast included the sacred, the erotic, the domestic, the political, the psychological, the commercialized, the medical, and the

liberated breast (Yalom, 1997). Each of these iterations was developed using the social context and cultural definitions of breast at the time.

Prior to the current/common/Christian era (BCE) and through to the 15<sup>th</sup> century, the prevailing representation of the breast throughout the world had been that of a symbol of the sacred. Paintings, sculptures, and stories from that time attribute the birth of values, power, and even the Milky Way to the breast and breast milk. Women's role was seen largely linked to the ability to feed young and sustain the family (Yalom, 1997).

It was not until the 1400s that representations of the breast took on a more erotic feel. These representations focused on the breast not as a source of divine inspiration or nourishment for babies, but as an object of male desire. Art began showing the breast without connecting it to the idea of breastfeeding, rather showing it as a symbol of feminine vitality and youth. Due to the emphasis placed on the beauty and the aesthetic role of the breast, wet nursing became quite common in affluent society in order to preserve the aesthetic of breast of the mother (Yalom, 1997). While the breast held a great deal of sexual and aesthetic attention in parts of Western Europe, the breasts took on different meaning in other parts of the continent.

In Dutch kitchens and homesteads, the breast was a centerpiece to the family's activities. Art, literature, and other writing from the time describe and show the breast as a place where the family came together. In this area of Europe, breast-feeding was the norm and seen as an integral piece of both motherhood and womanhood. Until a woman had nursed her child at her breast, full membership into the community of women was not achieved (Yalom, 1997).

The practice of wet nursing, the use of breast milk sourced from a woman who is not the mother of the child (Golden, 1996), came into question in the early 18<sup>th</sup> century. While there had been religious and moral arguments against the practice prior to the 18<sup>th</sup> century, wet nursing had still been widely practiced especially in upper- and middleclass homes. Children of affluent families would be sent to live with women hired to nurse them. Clergy and political figures during the 18<sup>th</sup> century were the loudest opponents of the practice of wet nursing. Breast milk was seen as lifeblood through which the characteristics, morals, and diseases of the milk provider would be passed. This practice was then seen as highly distasteful to many who endorsed ideals of classism, which equated lower classes within society with venereal diseases and loose morals. For opponents, breastfeeding needed to remain the job of the mother in order to nourish youth with lifeblood appropriate to their class (Yalom, 1997). In this example, the function of the breast was fundamentally connected to class and social standing.

Modern perceptions of the breast also vary. Today the breast and female form are used to sell anything from cars to men's cologne. The breast is seen as a symbol of both repressive patriarchy and a means of liberation. The breast is still connected to the feeding, nourishing, and emotional development of children recognized in public health taglines such as "Breast is Best" (Martucci, 2015).

While the ideal breast of the 17<sup>th</sup>, 18<sup>th</sup> and 19<sup>th</sup> centuries was small round and found high on the chest (Yalom, 1997), current societal perceptions are that individuals, especially men, value a much larger chest than had previously been the ideal (Thompson & Tantleff, 1992). Outside of the trends that have marked the different iterations of the

breast in society, one characteristic has held true throughout. That characteristic is the breast as a paired, often symmetrical, feature.

In all of these iterations of the breast in society, a number of questions regarding the breast persist. To whom does the breast belong? Does the breast belong to the partner who finds pleasure in caresses and gazes? Does the breast belong to the baby who nurses and is rewarded with the breasts' nourishment? Does the breast belong to the governments and societies to regulate and police, to determine its purpose, when the breast can be seen, and by whom? Does the breast belong to the physician who requires and recommends preventative health measures to heal and protect it? Or does the breast belong to the woman who finds the breast on her chest shielding her heart?

Using these conceptions of the breast, an individual may see their own or their partner's breasts as sources of sustenance, femininity, pleasure, or power. The way in which the breast is conceptualized often contributes in building a definition of the self for individuals. In her essay, entitled *Breasted Experience*, Iris Marion Young noted that,

in Euro-American culture, it is to my chest, not my face that I point to when I signify myself [...] If [a woman's] chest is the house of her being, from which radiates her energy to meet the world, her breasts are also entwined with her sense of herself. (Young, 1992)

The entwinement of the breast and the self becomes particularity problematic then when diseases of the breast such as breast cancer are introduced.



## **Breast Cancer in US Cultural History**

As opinions and cultural definitions of the breast have evolved in US culture, so to have perceptions of breast cancer and its treatment.

Many historians have remarked on the gendered character of cancer in society. Edward Shorter states, in *A History of Women's Bodies*, "before 1870 or so people thought that cancer was mainly a women's disease, because the only cases that were easily diagnosed were the 'external' cancers that effected especially women" (Shorter, 1982, p. 242). And Historian Leslie Reagan investigated the ways in which cancer, especially cancer prevention, was a gendered health topic in the United States. Gendered messages about cancer prevention placed all cancers, not just those unique to women's bodies, into the domain and responsibility of women (Reagan, 1997).

Victorian ideals of modesty and decorum, popular in the 19<sup>th</sup> and early 20<sup>th</sup> century, largely prevented many medical interactions between women and their male providers. Reagan stated, "despite the fact that male physicians attended most deliveries by the 1930s, cancer literature reveals that women continued to feel uncomfortable going to male physicians for gynecological examinations well into the 20<sup>th</sup> century" (1997, p. 1781). Social change had to take place before women would feel comfortable going to a male physician for what we would now consider standard preventative medicine (i.e. clinical breast exams or Pap smears).

Public health interventions worked to overturn the popular anxiety of women in being examined by male physicians, with health communications that derided their fears. Instead of focusing on the responsibility women had to preserve their modesty, health

and medical communication called this modesty 'false' and warned women of its inherent risks and consequences. According to Reagan, "in labeling Female modesty 'false,' the cancer campaign ridiculed women and their feelings and blamed them for cancer" (1997, p. 1781). Interestingly, the "false modesty" rhetoric, although not labeled precisely as such, continues to be an issue that is not as historic as one might think. Many cultures and groups of people living in the United States still place a great deal of value on female modesty. Many of these groups see disparities in outcomes of certain cancers (Mo, 1992; Austin, Ahmad, McNally, & Stewart, 2002; Guimond, & Salman, 2013), making how public health frames this issue a timely and important issue to consider.

The onus of cancer prevention could be perceived to lie handedly with women, given the messaging that focuses on the impact that cancer has on women. This perception is particularly evident when the social perception of risk as it pertains to certain diseases is examined. Although heart disease remains the biggest killer of women (CDC, 2013), prevention efforts and messaging still focus on the need for self-breast exams and regular mammograms over the prevention options possible for heart disease.

This cultural and historical groundwork lends well to the foundations and paradigms of script theory. Cultural messages and historical settings weave together to become a script that begins to guide individuals and societies in decisions about the behaviors and how those behaviors will be perceived. Throughout the lives of members of all types of communities, individuals watch others navigate society within the cultural and historical contexts in which they also live. Beginning early in life, babies and children rely on models of appropriate behavior: parents, siblings, friends, actors on television, or

strangers they encounter. The models that these individuals provide work within the larger script of societal norms and expectations. The messaging that individuals receive within their communities, including examples, models, norms, and expectations, helps those individuals to create personal scripts of how to behave in given situations.

### **Sexual Script Theory**

Sexual script theory, which examines the motivations for human behavior, comes from the discipline of sociology. Sociologists Simon and Gagnon, developed the idea that behavior, attitudes, and even what one feels is required, within any given interaction, can be explained by socially-constructed scripts. These scripts operate at multiple levels. At the first level are cultural scenarios. These scenarios, similar to those surrounding the meaning of breasts discussed above, give guidelines for the collective meaning of actions, behaviors, and social interactions. At the second interpersonal level, these scenarios are applied to the unique interactions that take place at given points of time in one's life. Finally, at the intrapsychic level, scripts connect personal wishes and desires to the social meanings of the scripts (Simon & Gagnon, 1986).

This theory has been used within many different kinds of interactions, but lends itself quite well to sexual interactions (Markle, 2008; Wiederman, 2005; McCormick, 1987). Within sexuality, script theory holds that our sexualities are not inherent or natural pieces of the self, but that sexuality is learned through cultural messages that we collect from the moment of our entrance into society (Markle, 2008). Using a common and pervasive script in the United States, the traditional script, provides an idea of what script theory is and the three levels that construct it.

At the cultural scenario level, the traditional script is the gendered roles and regulations that are constructed within society. Stereotypical of the traditional script at the cultural scenario level, in terms of gender and sexuality, it would be expected to see scenarios such as the “glass ceiling”, men in positions of power in society, or women raising children and managing the home. At this level, “the enactment of virtually all roles must reflect either directly or indirectly the contents of the appropriate cultural scenarios” (Simon & Gagnon, 1986, pg. 98). In order to enact the specific roles of this level of the traditional script, women are in passive, possibly submissive, roles and men in roles that characterize them as aggressors and achievers. When considering sex, a traditional-styled cultural scenario would posit that women are submissive, not desiring of sex. Women would be charged with the role of gatekeeper for sex and regulate the uncontrollable determination of the libidinous man.

Whether these propositions are an accurate description of our own society or not, it is easy to find examples that support societal adherence to the cultural scenarios that make up the traditional sexual script. Sitcom wives and girlfriends often withhold sex from their partners. A highly sexualized or wanton woman is usually seen as an abnormality or an aspect of plot rather than a typical member of a cast of characters. These are the cultural representations that enact the scripts that are accepted by a society. But the impact of social scripts are not just happening on the societal level, these traditional scripts guide the understanding of gendered roles in interactions at the interpersonal level.

At the interpersonal level, the traditional sexual script becomes a guide for one's own behaviors and attitudes. At this level, the follower of the script becomes an actor in the script process. Actors create an intrapsychic script using the cultural scenario scripts and by adapting and rewriting these scripts for personal use in order to reach desired outcome. The intrapsychic script links the desires of the actor to the social meaning of the various script options (Simon & Gagnon, 1986).

The traditional script at these levels might be a woman who feels the need to wait for a certain number of dates before engaging in intercourse with her partner. Her use of the traditional interpersonal script may be what she understands is expected of her in this situation or what is expected if she is not wanting to put herself into an interpersonal script associated with being easy or generous with sexual favors. Although there is a possibility that she whole-heartedly wants to have sex from date one, this interpretation of the interpersonal script (the intrapsychic script) allows her to become the character that the script requires her to be in order for her to embody who she may believe society wants her to be.

Not everyone agrees that this process is accurately representative of the scripts that we use in social interactions. Researchers Hannah Frith and Celia Kitzinger found that there is possibly another explanation of scripts that individuals and society personify. In their research, Frith and Kitzinger explored the possible scripts being used for sex refusal among young women. What they discovered was that there may be an active discursive aspect to the act of creating scripts. This discourse did not "simply reflect or express ready-made cognitive schemas; rather, scripts are actively constructed in

interactions through which people 'work up' events as scripted (or as breaches of scripts)" (Frith & Kitzinger, 2001, p. 216).

In their research, Frith and Kitzinger used focus groups of women to discuss refusal of unwanted sex. Data from these focus groups did not necessarily tell the story of the script of refusing unwanted sex, but aspects of scripts were present. The difference that these researchers found was that within the focus group venue a script was being actively created. The interaction of the participants with each other and with researchers created a unique discursive script that was unlike script theory in the traditional sense, but more closely related to the traditions of discursive psychology's script formulation. The act of discussion and social interaction in the research environment formulated a script of its own. Participants spoke together seamlessly by finishing each other's sentences or collaboratively speaking about the topic, as if simultaneously formulating a culture and norms as they discussed their refusal of unwanted sex (Frith & Kitzinger, 2001).

Whether script theory or script formulation theory is employed, both depict how these interactions may be socially constructed. Although script theory or script formulation theory alone may not completely explain the mechanisms of or variations in sexual interactions, together they contribute to an explanation of the cultural context of sexual interactions and the meaning behind the desires that may motivate an individual within those interactions.

When considering cancer, sex may be the last topic to come to mind. But should this be the case? To look closer at how cancer patients are typified in our society, script

theory may be useful in exploring the cancer patient script and how the actor of this type of script is treated within our society. Although no cancer patient script can be found in the literature, a description of this script can be created using societal representations of cancer and disease (Schover, 2004).

It is easy to presume that the cancer patient script would carry with it an absence of health. Health, or the appearance of health, has been identified as one of the most important physical characteristics for attraction (Stephen, Smith, Stirrat, & Perrett, 2009). Health in the cancer patient script would probably not be an intricate and multifaceted entity, including with it not only physical health but emotional, social, psychological health as well. It would appear as a dichotomy; either one has health or one does not. The cancer patient script may characterize the survivor as something delicate, fragile, and, although not a prevalent idea in the dominant culture of the United States, in some cases as being contagious or capable of bringing disease to others. Expectations of the actor within their script would probably be minimal, possibly limited to adhering to and being grateful for the advice of physicians or slowly dying. With all of these characteristics combined, especially noting the absence of health, it is hard to imagine the actor within the cancer patient script as a sexual being.

Although this description may be overly stereotypical or harsh, it probably comes close to the script in people's imagination upon hearing about a diagnosis of cancer and helps to explain why "sexuality, intimacy, and cancer are not usually considered together" (Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998). However, outside of

popular culture or in the medical and psychological literature, sex and cancer are not topics that have been completely divorced from one another.

One of the often-discussed aspects of the traditional sexual script is resistance and docility, perhaps merely symbolic, from women when faced with the possibility of sexual interaction (Frith & Kitzinger, 2001; McCormick, 2010; Wiederman, 2005). Within this script masculinity is associated with a constant need for, want of, or distraction surrounding sex, while the feminine actor has the job of controlling these urges and being the sexual gatekeeper in the relationship through the use of resistance. In practice, resistance may simply be a token action that the feminine actor may feel is necessary to her script. Even while her script is telling her to say no, within her intrapsychic script she may still fully intend to continue on. But what does this scene look like when cancer has been introduced into the bedroom?

Is there a unique intrapsychic sexual script during treatment, immediately post-treatment, and after years of survival adhered to by women who have been diagnosed with breast or gynecological cancers? Does sex in these cases look different at the intrapsychic level? Some research suggests that women in these situations may engage in sexual activity more for their partners than for themselves (Weijmar Schultz, Van de Wiel, Hahn, & Wouda, 1995). In this intrapsychic script does a woman hear, “he has done so much for me, I owe it to him” or “he’s been so patient with me, maybe I better”? Usage of script theory may allow us to explain or better understand of the mechanisms of disease when they intersect with sex and sexuality.



Researchers in London (Mitchell et al., 2011) spoke to 32 people with an array of sexual experiences about how they would describe their own sexual experiences. From these interviews, researchers found three themes in the way that respondents described their sexual experiences, creating a cultural script for these behaviors.

The first cultural level script was the biomedical script. For the respondents using this script, sexual encounters focused on function and the achievement of orgasm. The physiological and biological need for sex that defined the biomedical script was engaged in with the goal of orgasm or reproduction. The next cultural level script was the relational script. For respondents using the relational script, sexual encounters focused on the bond shared between partners and the development of relational intimacy. Finally, researchers found that some respondent used an erotic script. For respondents using the erotic script, sexual encounters were focused on recreation and pleasure (Mitchell et al., 2011).

These three scripts can also be used to describe the extent of literature, and gaps persistent, related to issues associated with sex after cancer diagnosis and treatment.

### **Biomedical Script in the Literature**

A wealth of literature exists specifically exploring the intersection of sexual function and those individuals who have been recently diagnosed or who are undergoing active treatment for cancer. This area of the literature includes information for both physicians and patients. Advice necessary for proper sexual functioning throughout treatment, possible changes and adaptations that will need to be made at each phase of treatment are included in this body of literature (Wilmoth, 2007; Ferguson et al., 2012),

and a proposal that healthcare providers above all should be implicated in discussing, addressing, and communicating any issues that should arise (Hordern & Street, 2007; Barbera et al, 2011). At times literature touches on the psychological effects that cancer and its treatment may have on the individual, but this is by no means the objective. Possible practical steps to take for emotional wellness are often deferred to counseling or psychological staff.

Within this arena of the literature, a biomedical script of sexuality is by far the most abundant. The biomedical script puts an emphasis on sexual function and mechanisms of reproduction. The biomedical script acknowledges a base need for sex and identifies sexual activity as a basic right afforded to us by nature of being human. In this script, penetration, erection, and ejaculation are paramount, with the single biggest threat being the loss of the ability to complete these actions (Mitchell, Wellings, Nazareth, King, Mercer, & Johnson, 2011).

In a good deal of literature within this arena there is an emphasis on dysfunction and disability, while ignoring an exploration of pleasure and satisfaction. Common words or phrases include coping (Reese, Keefe, Sommers & Abernathy, 2010), sexual problems (Burwell, Case, Kaelin & Avis, 2006), sexual dysfunction (Brotta et al., 2008), and even sexual morbidity (Lindau, Anderson, & Gavrilova, 2007). The unconscious assumption being that there is a good chance that something will be broken and in need of fixing when a cancer diagnosis is made.

In focusing on the topic of sexuality from a biomedical perspective, several matters are lost. Since sexuality is much more dynamic and complicated than function

alone, 'fixing' sexual dysfunction may not serve the intended purpose of 'fixing' the patient. More complicated issues may be at hand including body image, intimacy, or threats to what the patient may feel makes her a woman. While the intended focus to function of sex and divergence away from physiological or emotional information within this set of literature could be considered a fault, at the same time it is important for practitioners of the biomedical script to understand the limitations of their expertise.

### **Relational Script in the Literature**

Another direction that the literature concerning sex and cancer takes is to consider individuals who have been recently diagnosed or who are undergoing active treatment and their intersection with a broader definition of sexuality. This type of literature may include information on mental health, gender identity, pleasure or satisfaction. This area of the literature is predominately occupied by the fields of mental health, with practitioners such as counselors and psychologists.

From this type of literature, a relational script of sexuality is most often used. Within a relational type of sexual script, sex is used to create bonds and relationships with partners. Sex in this script becomes an intimate act between two people who share feelings for one another. In looking at sex through a lens that emphasizes interaction between individuals, there is a connection between sex and the relationship within which that sex occurs. Quality of sex is inextricable from the quality of the relationship. Actors who use this script are looking for security or balance to come from an emotional connection interrelated to sexuality. The most significant risk to this script would be a loss of intimacy with a partner or a loss of relationship quality (Mitchell et al., 2011).

This script works upon the premise that "for most healthy men and women, sexuality is central to their lives and contributes to their personal and relational quality of life. For patients with a chronic disease, sexuality is also a significant determinant of quality of life, with sexual intimacy, being an important mode of communication with partners (Verschuren, Enzlin, Dijkstra, Geertzen, & Dekker, 2010).

Using literature from the relational realm, one gets a much more dynamic interpretation of sexuality. Within this type of research, there is an importance placed on sexuality beyond physical health and function (Dizon, 2009; Weijmar & Van De Weil, 2003; Verschuren et al, 2010), emphasis on body image and its effect on sexuality (Li & Rew, 2010; Hopwood, Fletcher, Lee, & Ghazal, 2001), and an exploration of the emotional side of sexuality in the face of cancer (Katz, 2009). Moving away from mere function and dysfunction, literature of this type answers broader questions about sexuality with oncological patients.

Unfortunately, this area of the literature still holds to the ideals of positivism that are also found in literature pertaining to cancer and sexual function where weight is placed on the scientific method and experimentation. Due to the value placed on the ideals of positivism, another similarity that these two approaches in the literature have is an emphasis placed on quantitative data collection that loses the lived experiences and the stories of patients.

### **The Missing Script in the Literature: The Survivorship Script**

One area that the cancer and sexuality literature only begins to touch is the idea of survivorship, by taking only trivial notice of the time after treatment has ended.

Although not often stated as such and not researched with individuals who are years away from cancer treatment, tools and resources discussed at times are applied to a lifetime beyond cancer and treatment.

When the definition of cancer patients includes all survivors, indiscriminant of time away from treatment, considerably less information exists. Within the limited survivorship-type research, both quantitative and qualitative research methods use the words and stories of the women interviewed (Juraskova, Butow, Robertson, Sharpe, McLeod & Hacker, 2003) in order to explore survivorship and sexuality beyond the confines of time during treatment (Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998; Ganz, Desmond, Leedham, Rowlan, Meyerowitz & Belin, 2002; Dorval, Maunsell, Deschenes, Brisson, & Masse, 1998; Bergmark, Åvall-Lundqvist, Dickman, Henningsohn, & Steineck, 1999). These studies look at survivorship and sexuality anywhere from months to years post-treatment to determine the types of complications, successes, or quality of life changes that may have arisen due to having participated in cancer treatments such as chemotherapy or radiation. Within these articles, sexuality is usually identified as one of many aspects of quality of life that may be important to the survivor.

Unfortunately, few articles explore in-depth these most comprehensive definitions of both survivorship and sexuality. There are many issues that could be explored using a research lens that respects the full timeline of survivorship and a broad definition of sexuality. A major gap in the cancer and sexuality research is the role that pleasure and satisfaction have on sex after cancer, the impact that body image related to cancer treatment may have on survivorship or even the possible areas of resilience or

protective factors seen among women who have lived beyond cancer diagnosis and treatment.

## **Conclusion**

As discussed in Chapter 1, survivorship is on the rise in our country. Organizations, such as the Institute of Medicine, have highlighted the success that screening, early detection, and new treatments have had on increasing the number of women surviving cancer (Barton-Burke & Gustason, 2007). But with the increase in the survival rate of those women touched by cancer, there is also an increase in the number of women who feel the physical and mental effects of cancer and treatment throughout the remainder of their lives. Medicine has become adept at addressing cancer and eradicating it from the survivors of our populace, but public health still has a research role to play in how to address the aftermath.

Research and the medical community have worked to address sexual function in women who have experienced cancer (Wilmoth, 2007; Ferguson et al, 2012; Hordern & Street, 2001; Barbera et al., 2011). Unfortunately, less research has been done to understand the sexuality of survivors outside of the biomedical script. Using the biomedical script as the only lens misses the domains of sexuality that go beyond physical health and functioning (Dizon, 2009; Weijmar & Van De Weil, 2003; Verschuren et al, 2010; Li & Rew, 2010; Hopwood, 2001). In addition to this lack of research, the role that long-term survivorship may have within a woman's sexual health is also missing (Juraskova et al, 2002; Ganz et al, 1998; Ganz et al 2001; Dorval et al, 1998; Bergmark et al, 1999).

One way to frame a further exploration of women's lived experiences with sexuality and survivorship is through the lens of script theory. Describing the scripts that survivors use in interpersonal sexual interactions may be useful to understanding the types of issues that persist after a cancer diagnosis, if the experience of female survivors varies from the conventional sexual scripts, and how this new script may differ.

There are also many questions that the breadth of survivorship and sexuality research has yet to address. Topics in this arena include the important role and unique experiences of co-survivors. Although the importance of these individuals in the process is understood, little is known about how a cancer diagnoses may affect them and their own personal sexualities. Additional research must also be conducted to understand sexuality in the context of recurrent and metastatic disease. Within this area more exploration is needed in understanding the differences that may or may not be present between survivors at these stages of disease and those with less progressed cancers.

Although much of the extant literature is a call to physicians and healthcare providers to understand and better address the sexual needs of their patients, this approach may not be the most efficient or even appropriate way of going about understanding sexuality among cancer survivors. A focus on the biomedical script from this group leads to an emphasis on function and dysfunction over a more holistic definition of sexuality. The importance of function should not be down played, but an understanding that function is not the end all to sex and sexuality is vital.

With lengthened lifespans and a new importance placed on the idea of survivorship, life after cancer has become a more prevalent, more important and longer

lasting issue to address. More and more emphasis is being put on a patient's life after the treatment has come to an end. Unlike many disease treatments, cancer's treatment often leaves long-term, possibly life-changing, outcomes. Surgery scars, loss of sexual organs, loss of sensation and the effects of chemotherapy, radiation, and hormonal management are often things that will be continually dealt with throughout a woman's life, well beyond the conclusion of treatment. These possible outcomes and the effect that they have on sexuality, gender identity, pleasure and satisfaction even beyond adequate function, are ready for exploration by public health professionals.

In order to better understand women's lived experience in navigating aspects of a comprehensive definition of sexual health after having been diagnosed with breast cancer, the purpose of this qualitative study was to investigate how women make sense of sex, sexuality, and expression of gender after having been diagnosed with and/or treated for breast cancer.



## **CHAPTER 3: Methods**

### **Qualitative Research Methods**

Creswell (2007) described five generalized methods for conducting qualitative research, but without a prescription for how these methods of research need to be completed. While some researchers may find one of these methods to be comprehensive for their needs, others may benefit from a combination of more than one of these methods, piece together parts of several methodologies, or go in a direction that may not adhere to any of the recognized methodologies of qualitative research (Creswell, 2007).

Combining two of Creswell's five approaches, the narrative and phenomenological approaches, was most appropriate for the current qualitative research endeavor. Aspects of both phenomenology and narrative qualitative research were interwoven to conduct this study.

### **Narrative Research**

Qualitative research using a narrative approach focuses on individuals' stories and experiences (Creswell, 2007). For Clandinin & Connelly (2000), researchers of education and instruction, "narrative is the best way of representing and understanding experience" (p. 18). "Life – as we come to it and as it comes to others – is filled with narrative fragments, enacted in storied moments of time and space, and reflected upon and understood in terms of narrative unities and discontinuities" (Clandinin & Connelly, 2000, p. 17). Individuals see and experience the world in which they live as stories and bits of plot. As incidents occur, these experiences are then fitted with the beginning, middle, and end of that particular persons' life story.

The importance placed on the timeline of an event is one benefit to narrative research (Creswell, 2007; Clandinin & Connelly, 2000).

When we see an event, we think of it not as a thing happening at that moment but as an expression of something happening over time. Any event has a past, a present, as it appears to us, and an implied future. (Clandinin & Connelly, 2000, p. 29)

Chronology was crucial to the examination of survivorship in this study. People's experiences and the way that they understand those experiences develop, change, and progress with the passage of time. The narrative of a person's survivorship from cancer grows and develops. Each new event or treatment adds to the overall story of survivorship.

### **Phenomenological Research**

Qualitative research using a phenomenological approach explores the lived experiences of individuals who have shared a common phenomenon, or perceived event or experience. This research approach is used by researchers who are interested in: "(1) how people interpret their experiences, (2) how they construct their worlds, and (3) what meaning they attribute to their experiences. The overall purpose is to understand how people make sense of their lives and their experiences (Merriam, 2009, p. 23)." At its core phenomenology allows a researcher understand how individuals make meaning of experiences, events, or situations in their lives (Patton, 2005). By painting a picture of the phenomenon, using research participants' intimate views of the event,

“phenomenological research is well suited for studying affective, emotional, and often intense human experiences” (Merriam, 2009, p. 26).

For this study, the phenomenon that was explored was the lived experience of women in regards to sexuality after having been diagnosed or treated for breast cancer. For this project, the domains of sexuality of interest included three parts. Particular attention was paid to sexual behavior, interactions within relationships, and the ways that these women alter how they express and perform their gender after the point of diagnosis and beyond.

### **Bracketing: The Role of the Researcher in Qualitative Inquiry**

An aspect of qualitative research that cannot be ignored is the bracketing of the lens that the researcher brings to the study along with the possible role or experiences that researchers have had prior to initiating research. As researchers begin to conduct a qualitative research project, they are asked to remove the lens of previous knowledge and experience and allow the participants of the research to paint their own picture. While there is recognition within narrative inquiry that “research interests come out of our own narratives of experience and shape our narrative inquiry plot lines” (Clandinin & Connelly, 2000, p. 120), even in these cases, bracketing of a researcher’s experience is still necessary. In a best case scenario, a researcher would be unfamiliar with the topic that he or she intended to study which would then translate to a more opened-mind and unbiased research.

In order to do this, I as a researcher need to disclose one very significant aspect of my personal life. Along with carrying the labels of student and researcher, I am also a

cancer survivor. As a member of this amazing group of women who have lived through, and possibly even thrived, after a diagnosis of cancer, I took pains to distance my own experiences and stories from the current research. To say that objectivity may be difficult does not begin to scratch the surface of how intimately entwined I am with this population, but does describe how seriously I understand the need to remove myself from the questions I ask and answers that I hear.

We live in a society where personal sexual satisfaction can often be associated with shame, embarrassment, and confusion. These sentiments are not something that we grow out of or which stops with the completion of sexuality education in high school. These sentiments may become a feeling or sense that many of us carry with us throughout our lives. When we translate these feelings to a time when how we express ourselves sexually may need to change or adapt, what does it feel like to talk to someone about concerns when they find the subject matter as embarrassing as you do? Do the questions even get asked? I began seeing a common theme of intense curiosity coupled with intense trepidation in regards to questions surrounding sexual matters, when I spoke with other survivors throughout my own personal journey. While I had no problem making my own oncologist blush with direct and detailed questions about how aspects of my treatment, condition, and disease may affect my sexual health, I quickly realized that many women's concerns were never being voiced.

I committed myself to putting great effort into ensuring that my story, perceptions, beliefs, and opinions remained quiet, while in the space created, the voice of these incredible women dominated.

## **Study Population and Recruitment**

For the current research, criterion-based sampling was used to recruit participants. This sampling technique is common among qualitative research using a phenomenological approach and allows the researcher to insure that all cases fit the criterion selected (Creswell, 2007). Interviews were conducted with women over the age of 19 (the age of majority in the state of Nebraska) who had been diagnosed with breast cancer in their lifetimes and were a minimum of six months out of treatment. Since many changes and adaptations may need to be made immediately following diagnosis and throughout treatment, six months was chosen to give respondents time to adjust to a post-cancer norm. After this interim six months, respondents were better able to look back and understand the adjustments and changes that have occurred since diagnosis and treatment. Participants were recruited based on self-report.

In addition to criterion-based sampling, snowball sampling (Goodman, 1961) was utilized to develop a pool of participants. Initial participants (Wave 1) were recruited from the principal researcher's professional networks. After the initial recruitment, additional participants were identified using Wave 1 participants' personal connections. To identify additional participants, respondents were asked for friends and acquaintances who fit research criteria and who may be interested in participating in the study. Each respondent was asked, "Can you identify three women who have been diagnosed with breast cancer, who would be interested in answering these same questions?" These potential respondents (Wave 2) were interviewed and additionally asked this referral question in order to recruit another pool of participants (Wave 3). Using Saturation

Theory, as described by Lincoln & Guba (1985), waves of participant were recruited until saturation of data had been reached. Saturation was deemed reached when there was continued redundancy in respondents' answers or when additional interviews did not contribute additional novel information that enhanced the understanding of the phenomenon (Creswell, 2007; Patton, 2015).

Due to the extent of information that was collected through semi-structured interviews and using guidelines for phenomenological and narrative research as described by Creswell (2007), a minimum of 15 participants were sought for interviews. All women interviewed within the sample were over the age of majority for the state of Nebraska (19 years of age), had been diagnosed with breast cancer, were a minimum of six months out of treatment, and were willing to share their time in order to talk about the ways that cancer has impacted their gender performance and sexual health. Twenty-one women participated in the semi-structured interviews.

### **Study Design**

In looking at the possible designs for the current research, a determination was made that the focus of the research would be to explore the experiences that women face in regards to sexual behavior, relationships, and expression and performance of gender after having been diagnosed with breast cancer. A deeper look at the experiences of these women was the goal, and their own words were used in order to explain and better understand this phenomenon. Benefits of the phenomenological approach included, 1) participants' thoughts and words stood on their own without being translated into a metric that may or may not fit the participants' intentions and 2)

themes reliant on word choice and grammatical expression were apparent in a way that would not be possible with a scale or Likert-type question. The use of a phenomenological approach allowed, commonalities and important themes in regards to the experiences of individual research participants emerged and coalesced to create the foundations of a better understanding of the essence of survivorship and sexuality in this population.

Each interview conducted with participants followed a semi-structured interview guide (Appendix A), which to an extent allowed the participants to steer the conversations. This type of research tool is incredibly useful for facilitating semi-structured interviews. In order to assure that during each interview topics of interest to the researcher were discussed, the interview guide allowed for sufficient structure while additionally allowing participants the liberty to discuss topics and themes that were important to them.

Research done out of the Boston University Medical Center illustrated the wealth of information that can be obtained through semi-structured interviews using an interview guide. During their study, researchers were able to identify six themes to survivors' perceptions about psychological and social support. Had the researchers entered into research with preconceptions about the answers that they would receive or with a more rigid interview style, many of these themes would have been lost. Had they asked about the support that the survivors had from their husbands only, researchers would have never discovered the importance that female support had on their health or what a huge factor perceived stress on caregivers had on whether survivors considered

asking for help. The interview guide in this example was used as a tool to better understand a phenomenon that researchers admittedly did not know enough about (White & Boehmer, 2012).

The value of the semi-structured interview was also illustrated during preliminary research to determine feasibility for this study. During the collection of pilot data, there were minimal questions posed about each survivors' partner. It became clear very quickly that this additional person played an essential role in all aspects of the survivors' lives. Many women even began to refer to their situation as being part of a partnership facing the disease. For example, many respondents began to change the subject of their narrative. Many of the women went from using first person singular subjects (i.e. "when I finished chemo") to talk about their disease, to a first person plural subject (i.e. "we finished chemo"). This phenomenon demonstrated to researchers that the partner played a much more integral part in the success of survivorship than had been initially considered. Had the respondents not had this space to discuss their experiences with the disease, this finding may have gone unnoticed.

By using a semi-structured interview guide, the current research succeeded in identifying trends and major themes within the larger subjects of cancer survivorship, gender expression and sexual health. This outcome would not have been possible with a rigid interview structure, which would have eliminated the possibility of encountering unintended or unknown themes. Research of this kind asks for researchers to set aside impressions and previous information that may bias them and puts a great deal of control into the hands of the respondent. In choosing this approach the broad



phenomena created by the intersection and interaction of sexuality and survivorship was able to be explored. This exploration could only be accomplished if researchers made certain that participants were given the freedom and liberty to express themselves and truly relate their story. This freedom is inherent in the use of the semi-structured interview guide.

In addition to data gathered through interviews, the interviewer also kept detailed notes about her interactions with participants. These field notes were used to establish the emergence of themes, communicate issues or possible inconsistencies in the use of the interview guide, and collect the impressions of the interviewer about the tone and the environment of the interview. This data source assisted in organizing the thoughts and ideas of the interview, and was also be used as a form of data.

Results were drawn from all primary data source collected throughout the project. These sources included interview transcripts, audio files, and field notes.

## **Procedures**

After review and approval by committee members and the University of Nebraska Medical Center's Institutional Review Board, semi-structured interviews were conducted with women who meet inclusion criteria (women over the age of majority for the state of Nebraska, who had been diagnosed with breast cancer in their lifetimes and were a minimum of six months out of treatment, and who were willing to share their time to talk about the ways that cancer has affected their sexual health).

Each semi-structured 60- to 90-minute interview, consisting of questions with time allotted for further discussion, was conducted with women who had agreed to

participate, who matched pre-determined criteria as outlined above, and who had signed informed consent paperwork. In order to respect the needs and the time of participants, each participant was given the choice of participating in the interview either in person or by phone. Of the 21 respondents who participated in an interview, three chose to have their interview conducted in-person. The rest of the interviews were conducted over the phone.

Interviews began with initial questions about the woman's background experience with her cancer diagnosis and treatment. Each respondent was asked to describe her diagnosis story with the researcher. Additional probing questions were included in the interview script to ensure that the researcher understood the types of treatment that the respondent received and to initiate the discussion about sexuality during that time. After background information had been discussed, the interview guide followed a script associated with the three levels of interaction posited by Script Theory (cultural, interpersonal and intrapsychic). Questions about the Cultural Script focused on what the respondent believed was expected of her as a woman within the US culture with probes related to how this may have changed after her diagnosis. Questions about the Interpersonal Script focused on sexual/intimate/family relationships in the woman's life with probes exploring changes and adaptations that may have occurred. Finally, questions about the Intrapsychic Script explored the respondents' personal role in sex and her body image after diagnosis.

Interviews were audio recorded with the permission of the interviewee. None of the twenty-one respondents declined audio recording. Each interview was transcribed

and transcriptions were kept on a secured password-protected server. QSR NVivo 10 (QSR International, Cambridge, MA) software was used to store and organize data, transcripts, and themes.

## **Analysis**

The researcher read each transcript until an overall sense of the contents of each interview was understood. From the information contained in the interview transcripts, broad themes were explored that were exemplary of the essence of the priority population's lived experience as that lived experience pertains to this research and the questions asked during the interviews (Colaizzi, 1978). Initial codes, based off the interview guide (top-down themes), as well as codes based on iterative analysis of transcripts (bottom-up themes) were used to understand themes present within the interviews.

Validity was checked constantly using principles outlined by Bernard and Ryan (2009). The researcher looked for information garnered from participants that did not agree with established themes and any evidence diverged from emergent findings was nevertheless included in analyses. Fact checking informants' accuracy is not possible within this type of study. In order to counter this limitation, the interviewer was trained to ask for clarification or further information if the participant seemed to be unsure of a response. Any response given by an interviewee was presumed to be accurate and an appropriate representation of the lived experience and perception of that participant. Throughout the entire process of analysis the researcher considered ideas and theories

that did not fit with conclusions that had been made, in order to make sure that she saw an accurate picture of the phenomenon being researched (Bernard & Ryan, 2009).

## **CHAPTER 4: Sexuality, Breast Cancer Survivorship & Script Theory**

**Abstract:** With new diagnostic technologies and treatment modalities available, more people than ever are living as cancer survivors in the United States, a large percentage of whom are breast cancer survivors. These new technologies and treatments have side effects that impact women's sexual health during treatment and throughout long-term survivorship from the disease. The purpose of this research was to understand the intersection of breast cancer survivorship and sexuality, including expressions and performance of gender, relationships, and sexual behavior. This study used semi-structured interviews, conducted with 21 Midwestern women at least 6-months post-treatment. Following traditions of narrative and phenomenological qualitative research, the women's own stories were used to explore the impact that survivorship, diagnosis, and treatment may have on a woman's sexual self.

### **Introduction**

Researchers with the America Cancer Society estimated that in the United States of America, 15.5 million people have been diagnosed at some point in their lives with cancer. Their estimates project that this number will increase to over 20 million by the year 2026 (Miller et al., 2016). Within this substantial population of people diagnosed with cancer, 3.1 million have been diagnosed with breast cancer (Simon, 2016).

Advancements in technologies and therapies for this disease have caused the prevalence of breast cancer survivorship in the United States to rise in recent decades. More people

now than ever before are living with the title of “breast cancer survivor” (American Cancer Society, 2012).

Breast cancer survivorship begins at the point of diagnosis and persists throughout the lifetime of the individual (Mullan, 1985). Side effects due to the disease and treatments prescribed can have impacts on the survivor that last months, years, and even decades past the termination of treatment. These side effects have the potential to impact all domains of health. Breast cancer survivors have a high probability of experiences with fatigue, nausea, and other physical symptoms throughout survivorship (American Cancer Society, 2012; Boston Women's Health Book Collective, 2005; Charif et al, 2015; Kirkman et al, 2014). However, diagnosis, treatment, and survivorship from cancer impact more than physical health (Dizon, 2009; Weijmar & Van De Weil, 2003; Verschuren et al, 2010). Survivorship from breast cancer also impacts women’s sexual health. Factors including gender roles and performance (Reagan, 1997), sexual pleasure (Henson, 2002; Katz, 2009), sexual satisfaction, and body image (Hopwood, Fletcher, Lee & Al Ghazal, 2001; Li & Rew, 2010) can be affected after the words “you have cancer” are spoken. These side effects of diagnosis and treatment are long lasting, persisting well beyond the time allotted for treatment (Wilmoth, 2007; Ferguson et al, 2012).

It is essential to explore the experience of women who have been diagnosed with breast cancer in order to understand the impact that diagnoses, treatment, and survivorship have on a woman’s sexuality and sexual behaviors in the months, years, and decades after a diagnosis of breast cancer.

### **Survivorship Defined**

The title “Cancer Survivor” was coined by Dr. Fitzhugh Mullan in 1985. Dr. Mullan, himself a cancer survivor, noticed that there was something about hearing the words “you have cancer” that made an individual inherently different from their non-diagnosed peers. According to Dr. Mullan, those three words created an experience for an individual altogether unique. Hearing those words linked that individual to others who have experienced the same occurrence. According to Dr. Mullan’s definition, survivorship from cancer begins at the point of diagnosis and ends at death. Whether the individual is cured, lives with the disease, denies treatment, or dies, the title of survivor persists. The definition lacks a more nuanced, theoretically based understanding of the underlying behaviors and perceptions within the social and sexual experiences of survivors.

### **Introduction to Script Theory**

Script theory attempts to explain peoples’ behaviors and perceptions within social interactions. Script theory is a psychological theory that hypothesizes that throughout one’s life, as one sees people, such as parents, peers, or even strangers interacting, that individual builds a script in their mind as to how these interactions should take place. That person then uses these scripts throughout their day and throughout their life (Tomkins, 1978). There are infinite places and interactions where people rely on these social scripts. For example, when a person enters an elevator, they rely on a script to know how to handle that situation and to do what is expected of them. Do not to speak. Face the door. Watch the lights as the elevator ascends. That collective script does not allow for behaviors outside of these ridged constructs. When deviations occur, those

deviations make individuals uncomfortable. When people enter a public restroom, a grocery line, or see a neighbor outside, they rely on these scripts in order to act appropriately and do what is expected of them in that situation. But the impact of these scripts goes well beyond social interactions in public spaces.

Sociologists, Simon and Gagnon (1986), believed script theory was an excellent way to explain human behavior and beliefs in sexuality and sexual interactions. They identified three levels of sexual scripts that dictated this type of human interaction: the cultural, interpersonal, and intrapsychic levels. At the cultural level of sexual scripts, cultural directives give groups of people a collective meaning for actions, behaviors, and interactions. Within this level of sexual script theory one finds gender roles and social expectations. Traditional scripts in this arena would include the idea of the “glass ceiling” that limits women’s ability to achieve success in the work place and the wage gap that exists between men and women in similar positions (Simon & Gagnon, 1986). This level of scripting also includes the many cultural expectations that society has of women’s sexuality, which include sexual passivity, modesty, and a libido that pales to that of men. A divergence from this script is met with name calling and denigration. Whether this is the personal position of individuals within the United State is irrelevant. It is the dominant script that people within the United States are shown when they read magazine, browse the internet, or watch television.

The second level of sexual scripts are interpersonal interactions. Within this level, individuals apply cultural scenarios to their own social interactions (Simon & Gagnon, 1986). For women, this level of the sexual script may be found when they experience,



and then apply the cultural scenarios that are listed above. For example, a woman may feel the need to reject sexual advances before submitting to them, even if she wanted to have sex all-along. She may believe that a certain number of dates or interactions need to take place prior to sexual activities with a new partner. At the risk of being labeled *easy* or *slutty*, she may also believe that any initiation of sexual activity needs to come from her partner.

Through the individual interpretation of the cultural and interpersonal scripts, one finds the third level of sexual scripts, the intrapsychic level. This level allows individuals to become the character that the script requires in order to embody who that person believes society may want them to be. At the intrapsychic level, this theory explains the development of “turn-ons” and sexual preferences. One example of this interpretation is the evolution of sexual desirability. While during the 18<sup>th</sup> and 19<sup>th</sup> centuries a voluptuous or curvy female form was the ideal, women are now pushed toward a slimmer figure including less curve and smaller breasts (Yalom, 1997; Swami, Gray, & Furnham, 2006). Cultural scripts for the expectations of the female form translate into desirability for that expectation by individuals within that society.

Individuals within societies rely on scripts in moments of intimacy and when they are alone. Script theory has been used to explain many different types of human interactions, but it works particularly well for sexual interactions (Wiederman, 2015). Script theory holds that human interactions are not dictated by genes or biology, but by the on-going script that individuals play within their minds. This sexual script is built by

the interactions that individuals see and experiences they encounter throughout their lifetimes. For this reason, script theory is a powerful tool for the current research.

As with the rest of society, survivors of breast cancer rely on scripts in their interactions with others and to build a personal identity situated within the society. When the script that an individual is using can be identified, subsequent behaviors or reactions can be filtered through that script to understand intention for future behavior. When the condition of breast cancer survivorship is examined this process may be disrupted. Because cancer has been introduced, there is interference or confusion in attempting to rely on routine scripts. If a survivor's intrapersonal identity relies on the traditional feminine script, breast cancer may cause her to question her place within society, her role in interpersonal relationships, and her identity as a feminine character. Script theory makes it possible to use scripts to explore survivors' perceptions of the world around them, intention for behaviors, and personal identity, making it well fit to the current research.

### **Statement of the problem and research question**

A biomedical approach is commonly used to understand the physical and emotional challenges of women who have experienced breast cancer (Wilmoth, 2007; Ferguson et al., 2012; Hordern & Street, 2007; Barbera et al, 2011). This approach limits the understanding of survivorship (Dizon, 2009; Weijmar & Van De Weil, 2003) and often excludes sexual orientation, behavior, and gender identity (Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998; Ganz, Desmond, Leedham, Rowlan, Meyerowitz & Belin, 2002).

This study explored the lived experiences of women who had been diagnosed with breast cancer, paying special attention to the expansive timeline of survivorship and the full breadth of domains that form the concept of sexuality. To this end, this qualitative study explored how women navigate sex, sexuality, and sexual intercourse after diagnosis and treatment of breast cancer, through four aims. The first aim was to explore the impact of cancer diagnosis and treatment on the sexual scripts of women who had been diagnosed and treated for breast cancer throughout their survivorship (lifetime). The second aim was to distinguish characteristics unique to breast cancer survivor cultural, interpersonal, and intrapsychic sexual scripts. The next aim was to explore the physical and emotional adaptations that women had to make after diagnosis and treatment of cancer. The final aim focused on determining if survivorship milestones (i.e. completion of treatment, the one-year anniversary of diagnosis) have an impact on the sexual scripts of women who have been diagnosed or treated for breast cancer.

## **Methods**

This study utilized methods from narrative research and phenomenological research. Narrative research focuses on individual stories and experiences. As posed by researchers Clandinin and Connelly in 2000, "life-as we come to it and as it comes to others-is filled with narrative fragments, enacted in storied moments of time and space, and reflected upon and understood in terms of narrative unities and discontinuities." Human beings use stories to understand the world around them and to make meaning of what they experience.

Using narrative qualitative methods of research allowed the timeline of events to

hold a crucial position in how each woman's story was interpreted. Each diagnosis or treatment regime discussed during an interview did not happen in a vacuum, but within a dynamic multi-faceted life. As Clandinin and Connelly (2000) wrote, "when we see an event, we think of it not as a thing happening at that moment but as an expression of something happening over time. Any event has a past, a present, as it appears to us, and an implied future" (p. 29). Women who participated in these interviews contextualized their stories within the past, present, and future. The stories and narratives of individuals are important when attempting to understand the social scripts that each person uses in making meaning of social situations and interactions.

Phenomenological research explores the lived experience of a group of individuals who share a common phenomenon. This research approach is used by researchers who are interested in: "(1) how people interpret their experiences, (2) how they construct their worlds, and (3) what meaning they attribute to their experiences. The overall purpose is to understand how people make sense of their lives and their experiences (Merriam, 2009, p. 23)." As with narrative research methods, phenomenological research methods explore how people make meaning of a specific phenomenon (Patton, 2005).

Especially beneficial to the current research, "phenomenological research is well suited for studying affective, emotional, and often intense human experiences" (Merriam, 2009, p. 26). The phenomenon of interest in this study was the lived experience of women in regards to sexuality after having been diagnosed with breast cancer. Each interview probed for information about sexual behavior, interactions within relationships, and the ways that participants altered how they expressed and performed

their gender after the point of diagnosis.

Women who participated in this study were previously diagnosed with breast cancer and had completed their active treatment for the disease. Survivors who identified as having a metastatic breast cancer diagnoses were excluded because active treatment would have been on-going. Participants were over the age of 19, to eliminate childhood cancers and to comply with the age of majority in the state of Nebraska. All participants identified as being “Midwestern” and were from cities and states within that area of the United States, to minimize the possibility of differing regional norms becoming a confounding factor in understanding this phenomenon. A large majority of participants were from Nebraska, although Illinois, Missouri, Ohio, and South Dakota were also represented within the participant pool. The mean length of survivorship was nearly 10 years, with a range of 10 months to 32 years. Table 2 presents participant demographics.

**Table 2**  
**Participant Description (N=21)**

<b>Years of Survivorship</b>	Range 10 months – 32 years	Average 9.94 years		
<b>Treatment Modality</b>	Surgery 20 (95%)	Chemotherapy 13 (62%)	Radiation 11 (52%)	Hormonal Therapies 16 (76%)
<b>Surgical Intervention</b>	Lumpectomy 9 (43%)	Mastectomy 6 (29%)	Bilateral Mastectomy 9 (43%)	Reconstruction 8 (38%)
<b>Location</b>	State	n (%)		
	Illinois	1 (4.8%)		
	Nebraska	15 (71.4%)		
	Missouri	2 (9.5%)		
	Ohio	1 (4.8%)		
	South Dakota	2 (9.5%)		

Interviews with 21 participants were conducted between March 2015 and August of 2016. Each participant was interviewed by the principal investigator, interviews were audio recorded, transcribed, and stored on a secured server. Interviews ranged from 13 minutes to 64 minutes, with an average interview time of 34 minutes.

Interviews began with a broad open-ended request (i.e. "Can you tell me your diagnosis story?") and continued to narrow through questions designed to elicit insight into the Cultural Script, Interpersonal Script, and Intrapsychic Script. Questions in the domain of the Cultural Script covered the participant's understanding and perceptions of women's roles and the performance of gender in the United States' society and culture (i.e. "How would you describe the role of women with regards to sexual behavior?"). Questions in the domain of the Interpersonal Script explored the survivor's relationships with other individuals with particular attention paid to survivors' partnered intimate relationships (i.e. "How would you describe your role as a woman in your relationship since your diagnosis?"). Finally, questions in the domain of the Intrapsychic Script investigated topics such as body image, personal sexuality, and the survivors' personal role in sexual behavior (i.e. "What do you see when you look at yourself (naked) in the mirror?"). Each of these three domains of script theory were further divided into three subdomains of Expression and Performance of Gender, Relationship, and Sexual Behaviors. (See Table 3 for interview format and Appendix A for full semi-structured Interview Guide).

Data analysis was managed with QSR NVivo 11 (QSR International, Cambridge, MA). An initial code book was created using only the semi-structured interview script.

Each transcript was read and coded, using this initial schema. After initial reading and coding, themes that emerged from the interviews were added to the code book and were applied to the transcripts. Using these top-down and bottom-up coding schema, a comprehensive code book was finalized.

**Table 3**  
**Semi-Structured Interview Format**

Domain	Sub Domain	Representative Questions
Cultural Script: Women's Role and Performance of Gender in US Culture	<ul style="list-style-type: none"> <li>▪ Expression and performance of gender</li> <li>▪ Relationship</li> <li>▪ Sexual Behaviors</li> </ul>	"How do you think women with cancer are seen within US culture?"
Interpersonal Script: Relationship with Partner and Others	<ul style="list-style-type: none"> <li>▪ Expression and performance of gender</li> <li>▪ Relationship</li> <li>▪ Sexual Behaviors</li> </ul>	"Did you feel you had any obligations as a survivor?"
Intrapsychic Script: Body Image and Personal Role in Sex/Sexuality	<ul style="list-style-type: none"> <li>▪ Expression and performance of gender</li> <li>▪ Relationship</li> <li>▪ Sexual Behaviors</li> </ul>	"How does being a survivor effect how you achieve sexual satisfaction?"

## Results

### Introduction

Findings emerged at each level of the sexual script. Overarching themes included the role of care-giving, impact of loss of breast tissue, and survival from breast cancer.

### The Caregiver Script

Questions posed to explore the cultural script of women within the United States elicited women's biases and understanding of how each respondent saw their own life positioned within the US cultural script. Nearly all respondents emphasized a perceived

traditional gender role imposed on women by society, to which they themselves did not prescribe. Most women in the study rejected traditionally held beliefs about their role as demure gatekeepers of sexual intercourse. Further, respondents did not believe their sexual needs to be secondary to the sexual needs of their partners.

One traditionally accepted aspect of this script that many of the women held was the role of women as caregivers. When women spoke about this theme during questions concerning the cultural script, they spoke of the societal expectation that care and caregiving were the role of women. At times this obligation was described as a social stereotype for the role of women within our culture. This caregiving expectation was seen both in the public and private sphere:

I think there are expectations around the kinds of jobs that we have, you know, I think we're supposed to gravitate towards care, caring supportive professions. Women who are trying to be leaders or who try to run for president or something get kind of slammed. (Allison, 10-year survivor)

Women have a big role in our culture. As you finished that question, the first word that popped into my mind was caregiver. Should it be that way?

That everyone should be a caregiver? I think that's what society puts onto women. They're there to be the, they're supposed to take care of everything. They're supposed to be the caregiver. (Gloria, 14-year survivor)

Many women listed the ways in which they cared for families and friends. For many of them, fulfillment and feminine identity was found in their role as a caregiver.



Often caregiving was discussed as a personal obligation that the woman believed described her life.

However, the role of caregiver became challenged at the point of diagnosis. Caregiving became a point of stress. Many of the women were unfamiliar with releasing control over the care of their partners or families. As interviews progressed to the intrapsychic domain, reversing the role of caregiver and becoming a care receiver became yet another assault to an individual's femininity.

It made it so that I had to let somebody take care of me which is not my personality. I'm a caregiver. And so, that part changed. I had to allow kind of a little role reversal when it came to that. (Franny, 4-year survivor)

Many of the women had a hard time being the object of concern or worry by those they cared for normally. Trauma came not only with losing a breast, but also in losing a piece of feminine identity as a caregiver.

### **The Scripts of Loss**

Women in this study experienced surgical interventions to treat the cancer diagnosis. These surgical interventions resulted in changes of the breast tissue and the appearance of the breast. Out of 21 participants nine women had had a lumpectomy (removal of the tumor with partial removal of the breast), six had had a single mastectomy (complete removal of breast tissue of the affected breast), and nine had chosen to have a double mastectomy (complete removal of breast tissue from affected and unaffected side in order to decrease risk of reoccurrence). Several participants submitted to more than one surgical intervention and one participant chose to have no

surgical intervention, choosing instead to have radiation. Eight participants chose to complete reconstruction with plastic surgery after these surgical interventions.

The loss of breast tissue impacted how women saw their bodies as feminine. Many participants noted that lumpectomies or mastectomies changed the way that they looked and the shapes of their bodies. Many described this as a masculinization of a characteristic that they associated with being a woman. "After I had my mastectomy it made me very angry [...] it was hard. When I had the mastectomy I felt like I looked manly and that was hard" (Patty, 2-year survivor).

For many women, the partial or complete loss of one or more breasts was not merely a change in how they looked but also a change to how they were able to seek pleasure. Even after six years of survivorship, one woman explained the challenge this way:

I don't have any good sensation feeling there. [My chest] is pretty much off limits to my husband now. It just hurts more than anything, if anybody is touching [my breasts], doing anything to them. I don't know if that will get better over time but right now my boobs are nothing to me sexually anymore. (Nina, 6-year survivor)

Perceptions of partners and future partners also factored into women's sense of their feminine selves. Many participants shared concerns about how this loss may impact their partner's or future partners' perceptions of their bodies.

I didn't look the way I felt he wanted me to. And that was very hard[...]

You know we see women on TV with big breasts and two of them. For me

that was really hard that I couldn't give that to [my husband]. (Patty, 2-year survivor)

This experience was especially true among women who decided to complete reconstruction after mastectomy. Many women with reconstructed breasts lamented the loss of sensation in a part of their body that had brought them pleasure during sex. One woman who had felt her breast had been a major erogenous zone throughout her life, was shocked when this was no longer the case. In her words: "I just like them to be left alone, so anymore they are not really a part of our sexual life [...] personally, my breasts are off limits" (Carol, 25-year survivor).

Many respondents were upset about surgeries that were painful with unexpected results. Even in cases where women were not upset with the outcome, participants still found themselves disillusioned by the results of their reconstruction. The loss of nipples was particularly distressing for several of the participants:

It's not as bad now [since the mastectomy], but I still feel like I look like a Barbie doll because I don't have nipples. I don't have you know the breasts that I did. You know right now they don't look real. (Patty, 2-year survivor).

For those women who did not choose to reconstruct their breast many found another form of body modification to be helpful, choosing to counteract negative self-images with artistic, meaningful, or nipple tattoos.

I used to look in the mirror and ... I have a mastectomy on one side, I don't have a nipple on that side. But, when I turned 50, me and my twin sister

and our spouses went to Hawaii. And, had a nice birthday celebration hitting 50. And, this is crazy, but I went into a tattoo parlor. And I had a tattoo artist, right above my scar, put a pink breast cancer ribbon. It makes me smile. And I am not looking at a scar, I am looking at my little cute pink ribbon. (Carol, 25-year survivor)

One of the things that I did was decided not to get nipples reconstructed and instead I waited until the scars were healed enough and I had a really cool tattoo across my chest. Across my scar, from one end to the other and where nipples were gone I had two flowers. I think that maybe immediately after I did that I looked in the mirror and could not see ugly, I could see pretty and you know took on a different meaning. (Kelly, 2-year survivor)

For each of the women, breasts had been a source of sexual pleasure and/or a link to identity as a feminine being. With the loss of breasts or breast tissue both pleasure and identity were challenged. For some it forced a reassessment of sexual satisfaction, for others a reevaluation of what made them a woman.

### **Script of Survival**

Another theme that was present within the narratives of women in this study was the Script of Survival. Within this script, women downplayed their sexual needs or concerns and placed priority on surviving from the disease.

At the cultural level of interaction, many women felt that survivorship came with an obligation to get better and survive. These perceived obligations from others put

health and wellness at the forefront of the survivor's life and placed sexual needs and wants on an indefinite backburner. One participant noted that:

People with cancer don't have sex. Of course they don't, you know like they're just sick and, you know, nasty and whatever. They're not supposed to be having sex with people. They're supposed to be focusing on getting better and you know making their mark on society by doing charitable work. (Allison, 10-year survivor)

Following this cultural script of illness precludes individuals from engaging in sexual activity with the intent to achieve pleasure. In the example of this particular participant, that belief related directly to her thoughts about what she deserved in a sexual relationship. When asked about sexual satisfaction, she had this to say:

I see myself as being deserving of less of other people. I mean I guess I would say that I'm damaged. So I would probably say for me satisfaction is making other people happy. Like if, if I get something out of it great, but I don't expect it and I don't focus on it. And umm that's probably incredibly unhealthy, but umm I think that's just how I feel. I sort of feel like, you're sort of the day old bread and you should be lucky to get anything and don't complain about it. I would say for me it would probably be more about making other people happy. (Allison, 10-year survivor)

At the interpersonal and intrapsychic levels, for women who identified with this script, there were perceived obligations to health care providers and partners that gave women the sense that energy used seeking pleasure through sex was frivolous in

comparison to energy dedicated to working to survive from breast cancer. When asked whether doctors and healthcare workers had spoken to survivors about sexual health needs since diagnosis, all participants stated that no healthcare professional had spoken to them about sex, sexual satisfaction, or sexuality. Some saw this avoidance of the topic as a mistake by healthcare workers, but most participants saw this as outside of the prevue of healthcare providers' positions. As one participant stated, "No, they only had time to treat people, you know" (Lisa, 32-year survivor).

Participants felt this obligation from partners as well. Some women felt that their relationship had grown in the face of the disease. But even when this was the case, the lingering sentiments of survival still prevailed. One example of this was a participant who downplayed the role of sex in her relationship, emphasizing that survival had been her and her partner's priority and continued to be the priority eight years later. In response to questions about sexual behavior changes that needed to be made after treatment and surgery she responded by saying:

I think that we grew to love each other even more knowing that I lived through a cancer diagnosis and you know, you know we were both scared. He cried, he cried too you know. It was a scary scary time for us, especially with two little boys you know we had young children at the time. I think we're just forever grateful that I survived. (Carol, 3-year survivor)

Many women felt a decreased libido and need for sexual activity. However, even with a decrease need for sex and the addition of pain or mobility issues, many women still engaged in sexual intercourse with partners.

There was a lot of damage there and so a lot of times if he would be touching me, in my mind I would be going, "Oh my god that hurt." But I don't say anything. I just let it happen, even though it was killing me.

(Denise, 15-year survivor)

The themes that emerged from the interview data focused on three different scripts used by participants throughout their survivorship. These script themes included care-giving, loss, and survival. Participants internalized these three scripts in interactions with others and society, using the script to make-meaning of interactions and situations with which they were presented.

## **Discussion**

Many of the biological and physiological side effects that women are told to expect when receiving treatment for breast cancer were present in the narratives of respondents from this study. It was not uncommon that women experienced all the side effects described within the literature devoted to the biomedical script. As seen in other studies (American Cancer Society, 2012; Boston Women's Health Book Collective, 2005; Charif et al, 2015; Kirkman et al, 2014; Henson, 2002) generalized pain and fatigue made vaginal intercourse uncomfortable and often unwanted; vaginal dryness was a challenge for many and all respondents who had received chemotherapy also experienced hair loss. However, these physical side effects were minimally distressing when compared to many of the other effects that came along with the disease and its treatment.

These longer lasting impacts challenged the pre-diagnoses script on which women relied during their lives. To varying degrees, participants used the traditional

script to structure interactions throughout their lives. This traditional gender role, found within this script, was similar to that described by Simon and Gagnon (1985). In their personal lives respondents adhered to this traditional script to varying degrees; however, each recognized this script as the predominant script required of them within society. Within this script, women and their needs are second to their male counterpart. Additionally, women are demure gatekeepers of sexual intercourse. Few participants found these aspects of the traditional feminine script to be true of sexual interactions with partners. Other features of the traditional feminine script, however, were relevant for participants.

For many respondents, cancer treatments and later assumptions of fragility from others challenged women's own perceptions of their roles within the traditional cultural level script. Previous research by Toliver (2016) found caregiving to be an important aspect of the feminine gender role for many women. The current research also found this theme to be persistent with a majority of respondents listing caregiving as an essential role held by women in our society. Although no respondent identified the loss of her caregiving status as an assault to their identity as a woman, the line can be drawn between the two when the cultural script outcome of "women are caregivers" found in interviews and the intrapsychic script of the individual who is challenged by disease to care for herself and others are merged.

Further evidence for the importance of the care-giving script came from the absence of a representative quotation found in discussions of the interpersonal level. Although care-giving was discussed a great deal, only vague references were made to



support this script during discussion pertaining to the interpersonal level. It was difficult to identify a representative quotation that supported the theme of care-giving at the interpersonal level. Upon closer scrutiny of this part of the data, the reason that a representative quotation did not exist became clear. The theme of care-giving was everywhere, just not explicitly discussed. The theme weaved itself throughout the conversations with interjections such as “especially with two little boys” (Carol, 25-year survivor) or asides like “my sister-in-law and brother-in-law were staying with us at the time” (Winnie, 11-month survivor). In each conversation, the fact that the participant was caring after the people who surrounded her was implicit, as if so obvious as to not warrant discussion. The absence of overt quotation about this topic is evidence of the prominence that care-giving has in participants’ scripts.

The impact of physical discomfort and pain combined with emotional discomfort, distorted self-image, and psychological stress made physical and psychological adjustments necessary after losing breast tissue. Although much research has been done showing a possible positive mental health and self-esteem impact of reconstructive surgery after a mastectomy (Rowland, Holland, Chaglassian, & Kinne, 1993; Juhl, Christensen, Zachariae, & Damsgaard, 2017), findings from the current study did not demonstrate this positive impact. Reconstruction often did not ameliorate the physiological distress of losing a breast. In fact, for those participants that had submitted to surgical reconstruction, the procedures did not lead to anticipated aesthetic outcomes and meant an often-unanticipated loss of sensation in the breast. This outcome made a significant impact on the intrapsychic script of many women. Femininity was connected

with the feminine form, which for some participants was perceived as lost after breast cancer.

Throughout each individuals' survivorship a heavy emphasis was placed on being healthy and doing everything necessary to survive and to beat cancer. Often this perception of the importance of being healthy and healing, coming from partners and healthcare providers, stood in contradiction to seeking pleasure and satisfaction through sexual activity. The result was women who did not see themselves as worthy of wanting sex.

Participants' interpretations of their personal scripts after diagnosis demonstrated the socially-constructed nature of scripts. Each script theme that was identified came from the abundant cultural messaging regarding the social position and role of women and the preferred aesthetic of the female form. The result of this messaging was social stigma regarding sex when associated with the breast cancer survivor. Participants in this study perceived this stigma and embodied it in interactions with healthcare providers and intimate partners. In attempting to follow perceived scripts, participants engaged in sexual behaviors despite discomfort and at times pain and were reluctant to bring sexual issues into clinic offices to discuss with healthcare providers. Scripts that participants had relied on prior to diagnosis were adapted to their new situation, but many times to the detriment of the participant.

### **Limitations**

This exploratory study included participants from the personal and professional networks of which the principal researcher was a member. Thus, respondents may have

been more homogenous than might be representative of the population of Midwestern female breast cancer survivors. Some characteristics were over-represented within the participant pool, including white race and heterosexual orientation.

## **Conclusion**

For the women in this study, the physiological and psychological impacts of cancer lasted well beyond initial diagnosis and treatment. Whether months or decades after diagnosis, cancer continued to leave a mark on the gender identity, sexuality, and sexual activities of the women within this research. The meaning of survivorship and the perceived role of the survivor depended on that individual's interpretation of relied upon scripts adopted to breast cancer survivorship.

These socially-constructed scripts have implications for future public health practice in the realm of survivorship. Future research and interventions regarding sex and cancer survivorship should include the role of stigma. Reducing and eliminating stigma, both from the survivor and the greater society, will be important for successful future programming.

## **Chapter 5: To Whom Belongs the Breast: a qualitative exploration of the complicated role of breasts after breast cancer**

### **Abstract**

The female breast fills multiple roles throughout a woman's life, which may include serving as a source of sustenance for young, an erotic and pleasurable organ, a source of feminine identity, or even a source of power. Throughout history, control of the female breast has been usurped by others, including government, society, family, and offspring. This qualitative study examined the ways in which ownership of the breast is perceived during breast cancer survivorship. This study found that throughout survivorship influences on the breast come from several sources. These sources include healthcare providers, intimate partners, and self. How these influences impact outcomes of cancer care and ultimately decision made about the breast are discussed.

### **Introduction**

Anyone with breast tissue has the risk factor necessary to develop breast cancer. However, women experience a disproportionate share of this disease. Men account for less than one percent of breast cancer diagnoses (Quincy, Williamson, & Winstanley, 2016). Conversely, one in eight women will be diagnosed with breast cancer in their lifetime (American Cancer Society, 2015). This disproportionate representation among women has led to a gendering of the disease. Prevention efforts are saturated in the color pink while awareness campaigns focus on the loss of the breast as an assault against the

female form. Evidence of this association between breast cancer and the feminine body are plentiful within U.S. society.

Many breast cancer awareness and prevention campaigns are focused through the lens of heterosexism. One common example of this heterosexism is the association of breast cancer with the pink ribbon and color pink broadly (Zavestoski, McCormick, & Brown, 2004). American consumers can find nearly any product pink-washed; there are pink foods, pink office supplies, pink pepper spray, even a pink cement mixer (Ryan, 2012). During the month of October, also known as National Breast Cancer Awareness Month, in cities like Philadelphia or Kansas City the fountains spurt pink water. These popular breast cancer awareness campaigns rarely center on the individual who has been diagnosed with the disease, but rely on the social construct of the sexualized breast (Zavestoski, McCormick, & Brown, 2004). T-Shirts and posters support this idea with slogans like “Save Second Base” or “I Stare Because I Care”. These type campaigns move the discussion away from the prevention of cancer as being a threat to a woman’s well-being or quality of life, and focus the discussion on the threat to pleasure that another may be denied. In these examples, the impact of breast cancer on the woman who is diagnosed is not a priority. The impact that this gendered lens may have on the woman who is diagnosed is absent.

The diagnosis and treatment of breast cancer for most women includes at least one surgery wherein breast tissue is removed. The amount of tissue removed is dependent on several factors including diagnosis and prognosis, recommendations of clinicians and surgeons, and individual characteristics of the patient. This invasive and possibly traumatic experience forces women to assess their relationship to their breasts.

These trends in how the breast is perceived and positioned within society are important because one's sexuality and embodiment of gender is informed by the society, religion, and culture in which one lives. Perceptions and interpretations of the breast are constructed from the social and cultural environment. In the Western culture, that social and cultural environment has created many different versions of the female breast throughout history. These perceptions are not concepts entirely external to the individual, but are also embodied by that individual. In effect, the perception of one's own body comes not only from the self but also from these external influences. To understand individual interpretation of the breast, one must understand cultural and societal interpretation. To understand the societal and cultural perception of breasts, breast cancer, and treatment for breast cancer play, one needs to understand the history of the breast and the role that the breast has played and continues to play in Western society and culture.

## **Literature Review**

### **Women's Breasts in US Cultural History**

The breast may be perceived as a source of sustenance for young, an erotic and pleasurable organ, or even a source of power. Theories on the biological and reproductive purposes of breasts come from evolutionary biology and evolutionary psychology. Within these fields the breast, beyond an organ for nursing offspring, is a mirror of the posterior and an evolutionarily selected trait that allowed prehistoric women to draw attention to the front of the body as humans began to walk upright and engage face-to-face in sexual

intercourse (Barber, 1995; Ryan & Jethá, 2010). While these may be the evolutionary beginnings for the human breast, these beginnings by no means constitute the comprehensive story of the current role of the breast in the lives of individuals and society.

Western, particularly American and European, conceptions of the breast have included the sacred, the erotic, the domestic, the political, the psychological, the commercialized, the medical, and the liberated breast (Yalom, 1997). Each of these iterations was developed using the social context and cultural definitions of breast at the time.

Prior to the current/common/Christian era (BCE) and through to the 15<sup>th</sup> century, the prevailing representation of the breast throughout the world was a symbol of the sacred. Paintings, sculptures, and stories from that time attribute the birth of values, power, and even the Milky Way to the breast and breast milk. Profound emphasis was put on women's role feeding young and sustaining the family (Yalom, 1997).

In the 1400s perceptions of the breast became more erotic. Thus, the breast became an object of male desire. Art began showing the breast without connecting it to the idea of breastfeeding, rather showing it as a symbol of feminine vitality and youth. Due to the emphasis placed on the beauty and the aesthetic role of the breast, wet nursing became common in affluent society in order to preserve the breast of the mother (Yalom, 1997). While the breast also held a great deal of sexual and aesthetic attention in many parts of Western Europe, other groups in the continent had other perceptions of the female breast.

In Dutch kitchens and homesteads, the breast was a centerpiece to activities. Art, literature, and other writing from the time describe and show the breast as a place where the family was able to come together. Breast-feeding was the norm and seen as an integral piece of both motherhood and womanhood. Breast-feeding acted as a rite of passage. Until a woman had nursed her child at her breast, full membership into the community of women was not achieved (Yalom, 1997).

In the 18<sup>th</sup> century, the breast became representative of class and social standing; thus wet-nursing became more common (Golden, 1996). Clergy and political figures during the 18<sup>th</sup> century were the loudest opponents of the practice of wet nursing. Breast milk was seen as lifeblood through which the characteristics, morals, and diseases of the milk's provider would be passed. Wet-nursing was then seen as highly distasteful to many who endorsed ideals of classism, which equated lower classes within society with venereal diseases and loose morals. For opponents, breastfeeding needed to remain the job of the mother in order to nourish youth with lifeblood appropriate to the child's class (Yalom, 1997).

Modern perceptions of the breast also vary. Today the breast and female form are used to sell anything from cars to men's cologne. The breast is seen as a symbol of both repressive patriarchy and a means of liberation. The breast is still connected to the feeding, nourishing, and emotional development of children recognized in public health taglines such as "Breast is Best" (Martucci, 2015).

While the ideal breast of the 17<sup>th</sup>, 18<sup>th</sup> and 19<sup>th</sup> century was small round and found high on the chest (Yalom, 1997), current societal perceptions are that individuals,



especially men, value a much larger chest than has previously been the ideal (Thompson & Tantleff, 1992). Outside of the trends that have marked the different iterations of the breast in society, one characteristic has held true throughout. That characteristic is the breast as a paired, often symmetrical, feature.

In all of these iterations of the breast in society, a number of questions regarding the breast persist. To whom does the breast belong? Several parties may believe that they have claim on this aspect of the female form. Partners may take ownership through pleasure, with caresses and gazes. Offspring may exact ownership over the breast with needs of nourishment from breastmilk. Governments and societies may also contribute to ownership of the breast through regulation and policing that determine when the breast can be seen and by whom. With requirements and recommendation for preventative health measures, healthcare providers also exact influence over the breast. How much is left for woman who finds the breast on her chest shielding her heart?

Using these conceptions of the breast, an individual may see their own or their partner's breasts as sources of sustenance, femininity, pleasure, or power. The way in which the breast is conceptualized often contributes in building a definition of the self for individuals. In her essay, entitled *Breasted Experience*, Iris Marion Young noted that,

in Euro-American culture, it is to my chest, not my face that I point to when I signify myself [...] If [a woman's] chest is the house of her being, from which radiates her energy to meet the world, her breasts are also entwined with her sense of herself. (Young, 1992, p. 215)

The inextricable entwinement of the breast and the self becomes particularly problematic then when diseases of the breast such as breast cancer are introduced.

### **Breast Cancer in US Cultural History**

As opinions and cultural definitions of the breast have evolved in US culture, so to have perceptions of breast cancer and its treatment.

Many historians have remarked on the gendered character of cancer in society. Edward Shorter states, in *A History of Women's Bodies*, "before 1870 or so people thought that cancer was mainly a women's disease, because the only cases that were easily diagnosed were the 'external' cancers that effected especially women" (Shorter, 1982, p. 242). Historian Leslie Reagan investigated the ways in which cancer, especially cancer prevention, was a gendered health topic in the United States. Gendered messages about cancer prevention placed all cancers, not just those unique to women's bodies, into the domain and responsibility of women (Reagan, 1997).

Victorian ideals of modesty and decorum, popular in the 19<sup>th</sup> and early 20<sup>th</sup> century, largely prevented many medical interactions between women and their male providers. Reagan stated, "despite the fact that male physicians attended most deliveries by the 1930s, cancer literature reveals that women continued to feel uncomfortable going to male physicians for gynecological examinations well into the 20<sup>th</sup> century" (1997, p. 1781). Social change had to take place before women would feel comfortable going to a male physician for what we would now consider standard preventative medicine (i.e. clinical breast exams or Pap smears).

Public health interventions worked to overturn the popular anxiety of women in being examined by male physicians, with health communications that derided their fears. Instead of focusing on the responsibility women had to preserve their modesty, health and medical communication called this modesty ‘false’ and warned women of its inherent risks and consequences. According to Reagan, “in labeling Female modesty ‘false,’ the cancer campaign ridiculed women and their feelings and blamed them for cancer” (1997, p. 1781). Interestingly, the “false modesty” rhetoric, although not labeled precisely as such, continues to be an issue that is not as historic as one might think. Many cultures and groups of people living in the United States still place a great deal of value on female modesty. Many of these groups see disparities in outcomes of certain cancers (Mo, 1992; Austin, Ahmad, McNally, & Stewart, 2002; Guimond, & Salman, 2013), making how public health frames this issue a timely and important issue to consider.

The onus of cancer prevention could be perceived to lie handedly with women, given the messaging that focuses on the impact that cancer has on women. This perception is particularly evident when the social perception of risk as it pertains to certain diseases is examined. Although heart disease remains the biggest killer of women (CDC, 2013), prevention efforts and messaging still focus on the need for self-breast exams and regular mammograms over the prevention options possible for heart disease.

Although some research has explored the experiences of women after a diagnosis of breast cancer, no known study has explored the impact that the perceived role of the breasts have for women, partners, and society after a diagnosis of cancer. The purpose of this study was to explore the role that external entities throughout society play in a

woman's decision making process and self-image during diagnosis, treatment, and survivorship of breast cancer. Current trends in how the female breast is situated within society and the many ways in which society and other individuals exact ownership over the female breast during disease were explored.

## **Methods**

### **Qualitative Research Methods**

Qualitative research using a narrative approach focuses on individuals' stories and experiences (Creswell, 2007). The importance placed on the timeline of an event is a benefit to narrative research (Clandinin & Connelly, 2000; Creswell, 2007). Chronology is crucial when survivorship is examined. People's experiences and the way that they understand those experiences develop, change, and progress with the passage of time. The narrative of a person's survivorship from cancer grows and develops. Each new event or treatment adds to the overall story of survivorship.

Qualitative research using a phenomenological approach explores the lived experiences of individuals who have shared a common phenomenon. This research approach allows participants to interpret their experiences, construct their worlds, and attribute meaning to their experiences. The overall purpose is to understand how people make sense of their lives and their experiences (Merriam, 2009, p. 23)." (Patton, 2005). This study, explored the lived experience of women in regards to sexuality after having been diagnosed or treated for breast cancer. For this project, the domains of sexuality of interest included three parts: sexual behavior, interactions within relationships, and the

ways that these women alter how they express and perform their gender after the point of diagnosis and beyond.

### **Study Population and Recruitment**

Criterion sampling was used to recruit participants. This sampling technique is common among qualitative research using a phenomenological approach and allows the researcher to insure that all cases fit the criterion selected (Creswell, 2007). Interviews were conducted with women over the age of 19 (the age of majority in the state of Nebraska) who had been diagnosed with breast cancer in their lifetimes and were a minimum of six months out of treatment. Since many changes and adaptations may need to be made immediately following diagnosis and throughout treatment, six months was chosen to give respondents time to adjust to a post-cancer norm. After this interim six months, respondents theoretically would be better able to look back at and understand the adjustments and changes that occurred since diagnosis and treatment.

In addition to criterion sampling, snowball sampling (Goodman, 1961) was utilized to develop a pool of participants. Initial participants (Wave 1) were recruited from the principal researcher's professional networks. After the initial recruitment, additional participants were identified using Wave 1 participants' personal connections. Using Saturation Theory, as described by Lincoln & Guba (1985) waves of participants were recruited until saturation of data had been reached. Saturation was determined reached when there was continued redundancy in respondents' answers or when additional interviews did not contribute additional novel information that enhanced the understanding of the phenomenon (Creswell, 2007; Patton, 2015).

Twenty-one participants were interviewed. All women interviewed within the sample had been diagnosed with breast cancer, were a minimum of six months out of treatment, and were willing to share their time in order to talk about the ways that cancer has impacted their gender performance and sexual health.

Each interview conducted with participants followed a semi-structured interview guide (Appendix A), which to an extent allowed the participants to steer the conversations. In order to assure that during each interview topics of interest to the researcher were discussed, the interview guide allowed for sufficient structure while additionally allowing participants the liberty to discuss topics and themes that were important to them.

The value of the semi-structured interview was illustrated during preliminary research to determine feasibility for this study. During the collection of pilot data, there were minimal questions posed about each survivors' partner. It became clear very quickly that this additional person played an essential role in all aspects of the survivors' lives. Many women even began to refer to their situation as being part of a partnership facing the disease. For example, many respondents began to change the subject of their narrative. Many of the women went from using first person singular subjects (i.e. "when I finished chemo") to talk about their disease, to a first person plural subject (i.e. "we finished chemo"). This phenomenon demonstrated to researchers that the partner played a much more integral part in the success of survivorship than had been initially considered. Had the respondents not had this space to discuss their experiences with the disease, this finding may have gone unnoticed.

In addition to data gathered through interview transcripts, the interviewer also kept detailed notes about her interactions with participants. These field notes were used to identify emergent themes, communicate issues or possible inconsistencies in the use of the interview guide, and collect the impressions of the interviewer about the tone and the environment of the interview. This data source assisted in organizing the thoughts and ideas of the interview, and was also used as a form of data.

Results were drawn from all primary data source collected throughout the project. These sources included interview transcripts, audio files, and field notes.

## **Procedures**

Semi-structured 60- to 90-minute interviews were conducted with women who agreed to participate, and who had signed informed consent paperwork. In order to respect the needs and the time of participants, each participant was given the choice of participating in the interview either in person or by phone. Of the 21 respondents who participated in an interview, three chose to have their interview conducted in-person. The remainder of the interviews were conducted over the phone.

Interviews began with initial questions about the woman's background experience with her cancer diagnosis and treatment. Each respondent was asked to describe her diagnosis story. Additional probing questions were included in the interview script to ensure that the researcher understood the types of treatment that the respondent received and to initiate the discussion about sexuality during that time. After background information was discussed, the interview guide followed a script associated with the three levels of interaction posited by Script Theory (cultural, interpersonal and intrapsychic).

Questions about the Cultural Script focused on what the respondent believed was expected of her as a woman within the US culture with probes related to how this may have changed after her diagnosis. Questions about the Interpersonal Script focused on sexual/intimate/family relationships in the woman's life with probes exploring changes and adaptations that may have occurred. Finally, questions about the Intrapsychic Script explored the respondents' personal role in sex and her body image after diagnosis.

All interviews were audio recorded with the permission of the interviewee. Each interview was transcribed and transcriptions were kept on a secured password-protected server. QSR NVivo 10 (QSR International, Cambridge, MA) software was used to store and organize data, transcripts, and themes.

## **Analysis**

The researcher read each transcript until an overall sense of the contents of each interview was understood. Broad themes were explored to address the aims of the study (Colaizzi, 1978). Initial codes, based off the interview guide (top-down themes), as well as codes based on iterative analysis of transcripts (bottom-up themes) were used to understand themes present within the interviews.

To check the validity, the researcher looked for information garnered from participants that did not agree with established themes and any evidence diverged from emergent findings was nevertheless included in analyses. Fact checking informants' accuracy is not possible within this type of study. In order to counter possible misunderstanding or accuracy issues, the interviewer asked for clarification or further information if the participant seemed to be unsure of a response. Responses given by



interviewees were presumed to be accurate and an appropriate representation of the lived experience and perception of that participant.

## **Findings**

In interviews with participants, many entities exerted influence over the role of the breast and the meaning of the breast for participants. These levels of influence consisted of societal, interpersonal, and personal influences that impacted the breast and perception of ownership of the breasts.

### **Societal Influences on the Breast**

Participants discussed social and cultural norms for women in the US during interviews. Many participants identified social or cultural pressures to be the kind of woman who can have it all, balancing work life, family life, and romantic life. One participant explained this social role of women by saying:

Working jobs, raising the kids, making meals, keeping up with the house, the laundry, the cleaning and everything. I think women are super important in society with raising kids. I think you know they are supposed to support their husbands as well and be supportive with all that but then into their job and their responsibilities. So it's a big balancing act. I kind of joke that in my next life I want to be a man.  
(Nina, 6-year survivor)

Many felt that the norms their mothers and grandmothers persisted in the pressures they themselves felt, "I just feel that us women are still looked upon being barefoot, pregnant, and in the kitchen" (Tina, 10-year survivor).

Each participant spoke of their perceptions of how women were viewed within the culture of the US and about societal pressures that fall largely on women. However, during this part of the interview, none of the participants identified social or cultural pressures focused on the breast. More evidence of participant's perceptions of the expectations of the breast, how it is displayed, or who holds control over the breast came from the interpersonal and internal levels of influence.

### **Interpersonal Influences on the Breast**

For many participants, partners had extensive influence over the medical interventions to which participants submitted. This influence was not overt but a subtle external authority that was leveraged,

My first thought was, you know, I didn't want a lumpectomy. I'm like, "Just get rid of the whole breast. I don't need it. I don't want it." And, I remember talking with my husband on the way home from our meetings with the surgeon and the oncologist, and I said something about decision. And he goes, "Well, I thought you made your decision." And I said, "I was thinking about having them both removed." And so we talked about that, and he, um, didn't want to go that extreme. Let's just get the one with cancer and there was no doubt about it. That boob was gone.  
(Harriet, 15-year survivor)

The determination of whether a participant would submit to reconstruction was also heavily influenced by partners, especially husbands. Many women willingly gave over this decision to husbands and other romantic partners. As explained by one participant:

I wouldn't have had any [reconstruction] done, but my husband is the one that talked me into having the reconstruction. He just said you're 33 years old, you're young, you don't want to have to mess with a prosthesis. And you know what, he is so right. I am so glad that I didn't end up with that choice. (Carol, 25-year survivor)

Interactions such as these were common among participants. Only rarely was the decision about surgical procedure not discussed within interviews. With suggestion and advisement, partners exacted influence over decisions that participants made about their health. This influence was not limited to healthcare decisions but also used as participants acclimated to their post-surgery bodies.

Participants also identified intimate situations after surgery and treatment when their bodies were not wholly their own. Some participants remained silent and passively gave over their breasts for their partner's pleasure. One participant described her submission to her partner's wants like this:

There was a lot of damage there and so a lot of times if he would be touching me and in my mind I would be going, "Oh my god that hurts." But I don't say anything. I just let it happen, even though it was killing me. (Erin, 2-year survivor)

Other partners showed impatience or anger when participants were hesitant to show their naked body after surgery. The hesitancy of nudity by participants was met with discussion and entreaties from partners. Partners were quick to assure participants that their body continued to be desirable and attractive. Some participants passively accepted the actions of others, while others bypassed the autonomy of the participant and dealt with hesitancy directly,

I was getting ready to shower one day, and he came in and grabbed my t-shirt and he pulled it up over my head. And he said, “We’re going to take a look now. And I love you. I don’t care if you have no hair, and you have no boobs. You’re not hair and boobs. This is us.” And by him doing that, I think that just... because I know that not everybody has that, you know. (Franny, 4-year survivor)

This example demonstrates one situation that participants found themselves in where their body was not perceived as entirely their own. Examples of this type of threat to autonomy occurred in with healthcare personnel as well.

Respondents recognized that autonomy over their breasts was fragile in the medical setting. This fragility over autonomy was especially the case when conversations about surgical intervention options were discussed. Many women found little discussion or choice over the surgical option that would be used. An example came from one participant who felt her options were not completely explained to her,

I don’t think that they tell a lot of women that they can do nipple sparing. They don’t have to have their nipples removed. That was never discussed with me. I said “What the fuck did you just do to me? You didn’t tell me this.” [...] I loved my breasts during intimacy. For me, this is a big loss, and you know, people are like, “You’re here today. You’re alive.” I said, “I’d feel alive with a lumpectomy.” (Erin, 2-year survivor)

Other participants found that surgical decisions were made by doctors with minimal to no input from the participant. Often these decisions were made during surgery: “When I went in for the mastectomy they were supposed to start reconstruction with the

expanders. But, because there was lymph node involvement, they just didn't do that," (Renee, 13-year survivor). Mid-surgery decisions were viewed as a way that participants were left out of their healthcare team. This disregard for autonomy within healthcare left many participants with the belief that decisions made about their breasts were not within their control, but threats to personal autonomy did not come from the outside world alone.

### **Internal Influences on the Breast**

Participants in this study found their breast held different roles at different points in their lives. The role that their breast held depended on the stage of life that the participant was in and the people surrounding her. Participants described their breasts before breast cancer, as sources of pleasurable sensations, evidence of femininity, link to children through the breast milk that sustained them, and sources of power in how they were displayed. Prior to cancer, many participants saw their breasts as tools for seduction, alimentation, or arousal. One participant explained this in talking about a typical night out prior to her diagnosis, "I was always ready to put those puppies out and put em' to work" (Allison, 10-year survivor). In each pre-diagnosis example, the breast as a tool was working for them. For many women, this assessment of the breast as a tool at the disposal of the participant changed after diagnosis and treatment, from one of cooperation to one of hostility.

While pre-cancer breasts were a functioning part of the body system, post-cancer breasts were problematic, shameful, and a source of fear and anger. Many participants no

longer saw their breasts as part of their sexual selves after surgery or treatment due to breast cancer. One participant explained her post-cancer breasts:

Your boobs are supposed to be this sexual thing unless you're breastfeeding, right? And so, I don't want them to be or I just don't feel okay with them being that. I just need people to look the other way. That definitely makes a change in the way that I do things. Umm, because that's where a lot of people, I mean everyone has different kinds of sex, but I think that's where a lot of people start and sort of work their way down on your body. I'm sort of like "just skip that", you know? (Allison, 10-year survivor)

In discussing their breasts post-diagnosis, participants personified their breasts and often spoke of them as entities apart from themselves. When one respondent was asked what she saw when she looked at herself naked in the mirror, she commented, "I see me, but just me without any boobs. You know what I mean? And let me say that I don't feel badly about that, because my boobs tried to kill me." (Denise, 15-year survivor). Rather than seeing breasts as an ailing piece of their own bodies, many participants characterized breasts as active external pathogens working against survival.

## **Conclusion**

Stories from participants built a narrative that reflected the current position of the breast and breast cancer in society. Interviews with participants revealed many aspects of the complicated relationship that US society has with the breast.

Participants did not feel complete ownership of their breasts. In some cases, ownership was relinquished freely or at least with minimal hesitation. The transition of

bodily autonomy to partners and healthcare providers was, at times, a relief to participants. In almost all cases where partners showed influence over participants' decisions and bodies, participants showed no anger or resentment toward partners who exacted control or influenced decisions. In many cases, these parts of participants' narrative were relayed with a sense of relief or contentment at having a partner who cared enough to step in. However, this sense of relief did not persist during interactions with health care providers.

Participants showed resentment when they perceived that healthcare providers were excluding them from decision that were being made. This perceived exclusion was another way in which participant breasts were not their own. Although researchers claim that new treatments available for breast cancer have increased autonomy for survivors (Zavestoski, McCormick, & Brown, 2004), participants believed that they had minimal to no power over surgical intervention decisions. This perception of powerlessness over surgical decisions was true of discussions prior to surgery and especially true for decisions that were made during surgeries. Survivors who do not perceive themselves to be a part of the decision-making process may be dealing with doctors who are compromising patient autonomy for their own medical opinion, but it may also be a side effect of disease.

Being told that one has cancer causes extreme distress (Schover, 2004). The level of distress shown by oncology patients be should be included as a vital sign in interactions with healthcare providers. A high prevalence of side effects of this distress, which including anxiety and confusion, has been found among breast cancer survivors (Holland, Watson, & Dunn, 2011). These side effects of distress make it very difficult for survivors to

understand, remember, and think critically about the options being discussed during appointments. For a survivor experiencing distress in the form of anxiety and confusion, information about treatment and surgery options available may not be heard or understood at the time of discussion. For many the result was the perception that she was not a part of the process, a process that included her body and her breasts.

With remarks like “they tried to kill me” and “they were gone,” in reference to breasts, participants perceived their breasts not only as beings apart from themselves, but also classified their breast as enemies. Future research is needed to understand the impact on perceptions of self and decision-making that occurs when survivors see their breasts as antagonists to survival. How often this disassociation occurs and the severity of the disassociation, in the thoughts and beliefs of survivors, is essential knowledge to fully understand perceptions of personal autonomy in the context of survivorship. If a woman has abandoned the idea that the breast belongs to her, this may change her engagement in the decision-making process.

If a woman persists in taking ownership of her breasts and demands complete autonomy over her body, a disassociation between the woman and her breast would not occur. That continued connection would allow for the potential of a louder voice in the decision-making process and a higher stake in the outcomes of treatment, as women recognize their breasts as part of themselves and not an enemy other.

Future interventions should recognize this possible disassociation to reduce contention felt by survivors towards healthcare providers and decisions made during care. Future interventions should work to preserve bodily autonomy of breast cancer survivors



by using multiple interaction points of discussion using various forms of presentation (i.e. audio, visual, demonstrative). Conversations among clinicians, surgeons, and breast cancer survivors need to include all the possible options available prior to surgery, along with the possible scenarios that may occur once that surgery has begun. Since diagnosis is a time of extreme stress for survivors, one interaction point or conversation may not be enough for that individual to understand and retain the information that is given. By allowing multiple points of conversation, healthcare providers will reduce the perception that their opinion is the only one that matters. This increased communication will give survivors time to familiarize themselves with the information about their diagnosis and make an informed decision about the future of their breast.

### **Limitations**

Initial participants for this study were selected from the principal investigator's social and professional networks. This type of participant pool may cause some homogeneity; however, a representative sample in qualitative research is generally not the objective. While the goal of quantitative research is the ability to generalize findings to other populations, qualitative focuses on the in-depth understanding of a particular group or phenomenon. Purposeful sampling, such as the sampling method used in the current research, of participants who are characterized by specific criteria allows researchers using qualitative methods the ability to look in-depth at a sub population and how a specific phenomenon may have had an impact on that sub-population.

## CHAPTER 6: Reflections from an Insider Researcher

“Each woman responds to the crisis that breast cancer brings to her life out of a whole pattern, which is the design of who she is and how her life has been lived. The weave of her everyday existence is the training ground for how she deals with this crisis.” (Lorde, 1980)

### Introduction

In June of 2010, it was I who heard the words that gained me entrance into the exclusive membership of cancer survivorship – a club no one, including myself, wants to join. But my own diagnosis story started a bit before this. In December of 2009, my husband and I were on our honeymoon in Peru. We climbed Machu Picchu, we ate ceviche, we hiked the ruins of the Incan trail, we tasted guinea pig, and we found a lump in my breast. Back in Nebraska, it took five months, several appointments with physicians, a mammogram, two ultrasounds, and a biopsy before the doctors were finally convinced that what we were dealing with was cancer. I was too young, I didn’t have the right symptoms, and I did not advocate for myself or what I knew to be the truth.

As Audre Lorde said back in 1980, while she dealt with making meaning for her own diagnosis, everyone deals with this news in their own way. I am no different. For me, healing would happen when I knew and understood more about my disease. I sought out any and all information related to my diagnosis. In 2010, I was the first in my peer group, even my parents’ peer groups, to have experienced a cancer diagnosis. Because of this lack of reference, I decided that the best thing for me to do would be to learn and

experience everything I could. In this way, maybe I could be helpful when a friend or family member was diagnosed in the future, I could be a reference tool for which resources to access, which support groups to avoid, or which healthcare workers gave the best shots.

I asked so many questions of so many people, but I started to realize that not all the questions that I had had answers. Throughout this real-life research, sex was absent. Sex was absent in my conversations with doctors and nurses. Sexuality was scarce in the information I was given about living a life well after cancer. Sexual side effects were listed along with the risks of recurrent cancers, heart disease, or even death, making them seem small or unimportant by comparison. In addition to this, warnings were there, but how to deal with these changes and who I could go to with my questions was not.

Having no answers, but infinite questions, is not a great situation for someone with access to the internet. Through my training and graduate schooling, I knew that WebMD or Googling symptoms was probably not a great idea, but I didn't need that anyway. I was a student, in a program housed at a medical school. I had access to the good stuff. Surprisingly, this also let me down. Physicians and researchers didn't hesitate to discuss the sexual side effects of cancer and chemotherapy, but hearing the actual experiences of women who had "been there" was absent. Discussions and information were highly medical and technical and didn't necessarily answer the questions I had. When they did begin to answer those questions, it was done in a way that was not physically or intellectually available to all. Words like sexual dysfunction and sexual

morbidity were scary. My imagination ran with phrases like these and soon fear and tears were the major themes of these explorations.

At this point I had already been introduced to script theory and was quite interested in its possible role in sexual interactions. Seeing my situation through the lens of that theory, I began to think about the many ways that my own experiences and perceptions might help to better understand what I was going through.

At the cultural/societal level, sex is crazy prevalent in our society, but I cannot say that this has been a positive influence on my own personal cultural script. The model of sexuality and sexual identity that we are fed throughout our lives by media sources of all sorts does not place much of an emphasis on female sexuality beyond the female sexuality expectations of others. In addition to this emphasis, conflicting messages persist. Women are sexual objects meant to please men, but women are also sexual gatekeepers keeping men in check. Women are victims in situations of sexual assault, but women are at fault for their victimhood in the way they dress or behave. Because of these and many more bizarre dualities, I couldn't find answers to my questions using the cultural scenarios that surrounded me (my cultural script).

Many people, including myself, have their first introduction to the concepts of sex and sexuality from school, both formally in the classroom and informally from peers. The model we see in school though emphasizes the topic as shameful and silly. I found this even at the graduate level of academia. While working towards my MPH, I had a poster accepted into the annual student research exhibition. The research had been a pictorial ethnography of ads on Craig's list. Since the entire data set was pictures from these ads, I

had chosen to display some of the photographs on my poster. To my surprise, I was asked to cover up any pictures of the naked male form. The pictures were deemed inappropriate for the audience. That audience? Faculty and students from the college of public health.

Not only do we teach and present through a lens of shame, for most education surrounding sex there is no discussion of pleasure or satisfaction. Sex is a physiological process that produces babies and giggles alone. If this is the background that you have been surrounded by throughout life, it may be hard to voice it as an important aspect of life when survival seems on the line.

At the interpersonal level, I had a hard time seeking answers to my questions. I had my doctor, but the script I rely on with medical care providers was of little help. My oncologist would enter the room and ask how I was doing. My Midwestern script would kick-in automatically. "Fine, and you?" I may have spent the whole last week in bed, but this was still the response he'd receive. I mean, I'd hate to be considered a complainer... to my oncologist. I often had to psych myself up for questions in regards to sex, while ignoring the script screaming in my head that I thought appropriate for the situation. The same ideas that I presented from the women who participated in this research were cycling through my thoughts. "He doesn't want to hear this." "This isn't his job." "The man saved my life, why would I bring him something so trivial." I had to do a lot of work to quiet this script and overcome the prescribed relationship that seems to be a norm between physicians and patients. He was not my boss, he was not my savior, he was another part of MY health care team who was working for ME.

Within my personal relationship, I also saw how the interpersonal script I had learned throughout my life played a part in the extent to which my own interpersonal script was knit together with the traditional sexual script. It did not matter how many times I reminded myself that female sexuality, my sexuality, and pleasure were important, I still had a continuously running script in my head from a life in a society that places a tremendous emphasis on male sexuality and pleasure. It was extremely difficult to think of my own sexual needs as of equal importance as those of my masculine counterpart. It was hard to look at my relationship and actions with my husband through anything but the script that I had been surrounded by my entire life.

Despite societal pressures that force scientific inquiry or mature conversations about sex to occupy spaces of privacy, if anywhere, individuals want to have these conversations. We want to learn about the opportunities held within our sexualities and we want to talk to professionals who can help us when issues arise, both in the face of morbidity and in its absence. This desire was ever present in the conversation that I had with the interviewees from this research project. Each woman I spoke to, thanked me for creating a space where these conversations could come into the light and all, although nervous about what would be asked of them, came to the table ready and excited to talk about their own personal experiences when sex and disease collided. Throughout interviews with participants I was able to explore and understand the intersection of these two domains. Not only did I come away from these conversations with a better understanding of this intersection, I also learned valuable lessons about research and my relationship to the processes of research.

## **Insider or Outsider? That is the Question**

One of the first lessons that I learned was about the impact of my own personal survivorship on my research. Whether to tell respondents that I too was a survivor or not was a big question at the beginning of the interviews. During the first interviews, I was meeting with individuals that I was connected to in some way. By about the sixth interview, I realized that the woman on the phone had no idea who I was or what I looked like. The tell-tale signs of survivorship that were a common part of my look (i.e. caps and head scarves) were not apparent to those participants who did not know me and who I only spoke with over the phone. I didn't know how this presentation or lack of presentation of my own survivorship might impact research, but I believed that this disclosure would in fact lead to some sort of impact.

On the one hand, would women share more? In which case, great! We would share a common language and background of experience, that may lead to better understanding of one another. Maybe having been a member of the community and likely having experienced many of the same fears and frustrations in the departments of sex and medical interventions would lead to an opening. If my experience as a survivor lead to more disclosure or a safer space for conversation, then I was happy to disclose and see where that might lead us.

But a more real apprehension was: would women who knew my situation share less? As with any community, not all survivors are the same. When a woman who has the advantage of naming herself as a 5-year, 10-year, 25-year survivor, how does she make meaning of the woman sitting across from her who mirrors that struggle that she had

been through so many years ago? Would she relate too much to me and in doing so not disclose information, thinking “of course she already knows that”? Or would she hold back, fearing her own success in the face of this disease be interpreted as arrogant or worse, temporary?

Worse yet, my own cancer is metastatic. How might this be interpreted? I was concerned that some respondents may feel that their own experience was dwarfed or insignificant as compared to a person in a perpetual disease state. After all, each of the women that I spoke with were able to say that they had been cured of the disease. I could not begin to count the number of times I have heard, “but that’s nothing compared to what you are dealing with right now.” Well, you know what? It isn't. This isn't because I'm suffering more than any person I spoke with, this is because pain, anxiety, and fear are different and manifest themselves differently for each individual. We cannot compare suffering. What you are dealing with right now really is nothing compared to what I am dealing with, but the reverse is also true. I did not want this to become a lens through which participants answered the questions that I posed.

In order to attempt to counter this possible confounder, at the end of each telephone interview, I disclosed my survivorship status. About half of the women that I spoke to (N = 21) had knowledge of my personal diagnosis, while the other half had no idea how intimately involved in the disease I was until after interviews. Most of the interviews (n = 19) took place over the phone, so for those who never saw me or my scarf-clad noggin, there is a strong possibility that this disease was not connected to me at all – at least not until the termination of the interview when I let each respondent



know about my own personal connection to this disease. I felt a responsibility that each woman should know that I was a part of the community, that I was looking out for the best interests of the community and that their story was being heard by an individual who had a stake in the game. I knew that my decision was right when I noticed that for many of the interviews, some of the richest data came after my disclosure when my interview had been completed. The atmosphere of the conversation changed from a researcher/participant interaction, to a comfortable conversation between old friends.

For research that I plan to do in the future, determining whether to disclose my cancer status will be taken care of during the planning phase of research. My personal disclosure of disease status had not come up as an issue during pilot interviews due to the relationships that I had with those first respondents. It was not until about the fifth interview of my dissertation research that I realized the person I was talking to had no reason to know that I too was a survivor. Through this research I have learned that whether I disclose my disease status makes an impact on participants within the study, so as I continue to establish my research agenda this issue will be determined prior to the initiation of any future studies.

### **Importance of the Survivorship Timeline**

Another lesson that I learned from this research is that survivorship is not the same for everyone and a person's identity with this title is largely dependent on where they are in the processes of diagnosis, treatment, and healing. Especially when we consider women who are currently in treatments such as chemotherapy and radiation. In pilot research I did with breast and gynecological cancer survivors, sex during treatment

was the last thing on their minds. For most of them, their diagnosis had been in the recent past and the effects of treatment made even activities of daily living taxing. For those participants of the pilot research, sex would have been a superfluous expenditure of energy that could have been better spent on working hard to maintain a pre-diagnosis life. When time has lapsed (for this research defined as 6 months post treatment termination) and *survivorship*, not *survival*, is a more accurate description of life, then this conversation is less clouded with learning to adjust to the position cancer has taken within your life. At this point individuals have a better ability to step back and recognize the impact that the disease has had.

For future research, I will hold to this timeline. Throughout this current research, there were no indications that significant adaptation to disease occurred after the 6-months post treatment milestone. Adaptation caused by the disease and acceptance of the post-cancer body as a new normal does continue after this milestone. However, the steep learning curve that marks the first months of cancer treatment begins to level off and adaptation and acceptance become more gradual. This timeline of survivorship becomes a lens through which women see their disease and lens like this are important to recognize as we interact with communities of interest.

### **The Fundamental Role of Personal Lenses, Assumptions, and Biases**

In my work as an instructor in the university in Omaha, I often ask my students where their ideas and opinions come from. Most of my students are from places around Nebraska where they have lived the entirety of their lives. Urban and rural students make up classrooms, but in most cases, urban is defined as the suburbs of Omaha, a

metropolitan area of less than 800,000 people. There is the occasional student from a larger city or metropolitan area, but for the most part the population of the classroom consists of Midwestern students who have spent their lives in Midwestern environments. So when I posit a question in the classroom, the answer is often heavily weighted toward the conservative upbringing that these students have had. "But why?" is an extremely challenging question that many of my students have never heard. Their answers are informed by the lenses of experience, assumptions developed by a lifetime of observation, and subtle biases that were probably heard around the dinner table.

The training I strive for with these students does not attempt to eliminate these lenses, assumptions, and biases, but requires that students recognize the existence of lenses, assumptions, and biases in every judgment and interpretation we make. My hope for the classroom is not to eliminate or change these factors, but for students to become willing and hungry to understand where their ideas are founded and formed, who had a say in what they believe now, and the impact of their natal environment on fundamental ideas they now hold onto so dearly.

Just like the students in my classrooms, researchers too bring with them lenses, assumptions, and biases to the work they do. The lenses, assumptions, and biases that we bring to the formation, analysis, and interpretation of our research are not inherently bad, but I had done the one thing that I advise each of my students not to do. I had inadvertently allowed these lenses, assumptions, and biases to tinge my objectivity without first recognizing they were there.

Anger was an extremely potent fuel for the passion with which I faced the questions I wanted answered. I was angry at how sex had been dealt with in my own, and so many others', treatments. I was angry that the answers to my own questions weren't readily available. But above all, I was angry at being sick, again. This does not mean that the questions I asked should not have been asked, simply that they were questions that may have been tinted with a personal ire I had not yet recognized.

My own experiences and attitude may have tinted the questions that I asked and the way that they were asked; however, I used skills learned in studying qualitative research to maintain objectivity. One way that I tried to preserve this objectivity was through a process of constant reflection. After each interview, I wrote my impressions and emotional reactions to the conversation that had taken place and kept these reflections with as part of my field notes. At the time of reflection and later during data analysis, I used these field notes to realize moments in the study where bias-laden judgements may have taken place instead. This process helped to ensure that I stayed grounded in the data. In future research I plan to continue this practice.

## **Conclusion**

I have learned a tremendous amount about the intersection of sex and disease. Not only have I learned about myself and my placement within the research that I do, I have also learned that the community of survivors is more incredible than I had ever imagined. At the risk of perpetuating the social stereo type of the "Superwoman Survivor", the women I spoke with and who participated in the many iterations and stages of this research are pretty amazing.

In the future, I want to replicate this study with cervical cancer survivors. The community of cervical cancer survivors, while I am sure is equally amazing, has characteristics that are not present with breast cancer survivorship. One of these characteristics is cervical cancer's association with sexual activity, through its association with the human papilloma virus (HPV). While breast cancer survivors have an 'out and proud' status within our society, cervical cancer brings with it stigma that is not associated with other cancers. This hidden group of cancer survivors has less community cohesion and an unknown number, due to lack of research, of cervical cancer survivors do not disclose their disease status with others. These are two factors completely unfamiliar to the community of breast cancer survivors.

Another population for possible replication of this study would be with young adult survivors. For decades now, cancer treatment and survivorship research has focused on the impact to older adults. This focus is understandable when we consider that many times cancer is the result of a lifetime of health behavior decisions, but cancer diagnoses are not uncommon in young adult populations where these health decisions have not had nearly the number of years to wreak havoc on the body. The needs of young adults are quite different than those of older adults. While older adult survivors may have to worry about disclosing their disease status with grandchildren, young adult survivors may have to worry about whether having children will be an option for them. While older adults may worry about the impact that cancer will have on their sex life, younger adults may worry about how to start a sex life in the face of disease. These

needs are extremely different between the two groups and the current solution of treating both groups similarly does not work.

Within these two cancer survivorship communities, research has the potential of great impact. Especially when the miniscule amount of extant literature on these subpopulations is considered. For my future as a researcher, I want to be a part of understanding the unique needs of these groups and how public health can have a hand in making improvements to quality of life happen.

## APPENDIX

## Appendix A: Interview Guide – Sexual Satisfaction and Survivorship

### Opening Statement

Thanks so much for taking the time to talk to me. My name is Aja and I am a doctoral candidate from the College of Public Health at UNMC. I am currently working on a project exploring sexuality of women who have experienced diagnoses of breast cancer. The definition of sexuality that we will use comes from a sexual health textbook used at UNO. For the purposes of this interview, sexuality is “the emotional, intellectual, and physical aspects of sexual attraction and expression” (Yarber & Sayad, 2013).

The interview will probably be 60-90 minutes. During this time I would like hear about your experiences as a survivor and how sex and sexuality has played a role in your life both prior to and since your diagnosis. Please feel free to ask questions of your own, tell me if you need a break, or want to stop. Before we get started do you have any questions for me?

[Start recording]

### Initial Questions

How long ago were you diagnosed? \_\_\_\_\_

When did you complete active treatment? \_\_\_\_\_

Was breast cancer your primary cancer? Have you been diagnosed with other cancers?

\_\_\_\_\_

[Go to interview guide]

### Conclusion

Thank you very much for your participation and for taking the time to talk to me about your experiences. I just have one last question for you. Can you identify three women who have been diagnosed with breast cancer, who you believe would be interested in answering these same questions?

[Stop recording]



Domain	Themes or Subdomains	Prompt Question	Probes
Background	Build Rapport	Let's start with your diagnosis story.	<ul style="list-style-type: none"> <li>• Surgery? Why did you choose this surgery?</li> <li>• Chemo?</li> <li>• Radiation?</li> <li>• Hormonal therapy?</li> <li>• During this time did anyone discuss sex, sexuality or sexual satisfaction with you? What did they say?</li> <li>• How would you define sex?</li> <li>• Where you in a relationship during this time?</li> </ul>
Cultural Script Women's Role and Performance of Gender in US Culture	Expression and performance of gender	How would you describe, from your own point of view, the role of women in our culture?	<ul style="list-style-type: none"> <li>• How have your thoughts on these expectations have changed since you were diagnosed?</li> <li>• How do you think that fits with your own vision of your life as a woman?</li> <li>• How do you think women with cancer are seen in US culture?</li> </ul>
	Relationship	What, roles in your opinion, do women play within a romantic relationship?	
	Sexual Behaviors	Again, from your own point of view, how would you describe the role of women with regards to sexual behavior?	
Interpersonal Script Relationship with Others and Partner	Expression and performance of gender	How would describe your role as a woman in your relationship since your diagnosis?	<ul style="list-style-type: none"> <li>• How would you describe your role in your family before and after treatment and diagnosis?</li> <li>• Would this/How might this have been different if you were a man?</li> <li>• Did you feel you had a role to play or obligations as the survivor?</li> <li>• How would you describe your relationship with your partner? (Speculate on future relationships)</li> </ul>
	Relationship	Tell me how survivorship has impacted your relationship; If not in a relationship, speculate	

Domain	Themes or Subdomains	Prompt Question	Probes
		on how this might impact your relationships going forward.	<ul style="list-style-type: none"> <li>• Before and after treatment and diagnosis?</li> <li>• How did having cancer or the treatment that you were prescribed create changes within your relationship?</li> <li>• How would you describe your role at home and with your partner prior to diagnoses? After your diagnosis?</li> </ul>
	Sexual Behaviors	Tell me how survivorship has impacted how you have sex and the kinds of sex you have.	
<b>Intrapsychic Script Body Image and Personal Role in Sex/Sexuality</b>	Expression and performance of gender	How have the ways in which you express your own femininity changed since your diagnosis?	<ul style="list-style-type: none"> <li>• Where/how did you learn to adapt your sexual behaviors after <ul style="list-style-type: none"> <li>• Diagnosis?</li> <li>• Surgery?</li> <li>• Treatment?</li> </ul> </li> <li>• What does sexual satisfaction mean to you?</li> <li>• Does sexual pleasure/satisfaction look different then prior to your diagnosis? How?</li> <li>• How does being a survivor effect how you achieve sexual satisfaction?</li> <li>• What do you see when you at yourself in the mirror?</li> </ul>
	Relationship	What do you think your partner thinks about your contribution to your sexual relationship? What impact do you think they might say your diagnosis has had on your relationship?	
	Sexual Behaviors	If it has, how has your role in sex changed since your diagnosis?	
<b>Conclusion</b>	Missed Information or Other Important Themes to Consider	Is there anything we haven't talked about in regards to sex/sexuality and survivorship that I should know?	<ul style="list-style-type: none"> <li>• What does a newly diagnosed woman need to know about sex after being diagnosed with cancer?</li> <li>• Where should this information come from?</li> </ul>

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