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NEGOTIATING EMOTIONAL ORDER: A GROUNDED THEORY OF THE  
SURVIVORSHIP PROCESS IN WOMEN WHO HAVE COMPLETED TREATMENT  
FOR BREAST CANCER

By

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A dissertation submitted to the Graduate School- Newark

Rutgers, the State University of New Jersey

in partial fulfillment of the requirements

for the degree of

Doctorate of Philosophy

Graduate Program of Nursing

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And approved by

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Newark, New Jersey

May 2013

## ABSTRACT OF THE DISSERTATION

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Women

Who Have Completed Treatment for Breast Cancer

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**Rationale:** Decades of research focusing on treatment and detection of breast cancer has promoted better outcomes in treating the disease and longer survival rates. Despite this there is a significant gap in the literatures regarding the survivorship process. Breast cancer survivorship needs to be fully understood by nurses and health care providers (HCP) in order to obtain optimal health outcomes for this ever growing population.

**Method:** Classic grounded theory was used in this study to explore the process of transitional survivorship from the prospective of women who had completed initial treatment for breast cancer. Approval by the Institutional Board of Research at Rutgers University and Faxton St. Luke's Healthcare was obtained prior to the commencement of the research. Twelve women, who had completed initial treatment for breast cancer were interviewed. Interviews were transcribed verbatim and analysis by constant comparison as described by Glaser.

**Results:** In this study, the basic social process describing how women with breast cancer perceive their illness and take action was negotiating emotional order. Participants were attempting to bring the psychological aspect of having breast cancer into a state of order by negotiating control with cancer, themselves and external factors. From the data a five

stages latent process of negotiating emotional order consists of: 1) Losing Life Order, 2) Assisted Life Order, 3) Assuming Life Order 4) Accepting the Things Cannot Control, and 5) Creating Emotional Order. This latent process also had a cyclical property as evidenced by the data collected from participants that had experienced cancer more than once or had a time period where they were being tested for cancer recurrence.

**Conclusion:** This research method provided this population of concern with a voice to assist nurses explore the dynamic challenge women experience once they have completed breast cancer treatment and enter extended survivorship. This study's findings may help healthcare providers who care for breast cancer survivors understand the depth and perpetual emotional impact that breast cancer survivors endure. This study will potentially serve as path for future research and aid in the understanding of the psychological impact that breast cancer has upon survivors.

## **Dedication**

To Michael for without you I would not be who I am.

Thank you for being my partner and looking into the future with me,  
for the sacrifices and for being an exceptional father.

To my boys: Connor, Daniel and Ryan. Your sense of humor and  
bright spirits inspire me.

To my mother Judith and my daughter Katherine, both ends of my spectrum.  
I hope my research affects both of your worlds and makes this world a better place for  
women to live in

.To Laurie, my dear friend since kindergarten, who began her journey into transitional  
survivorship as I began to write this dissertation. You made me love the survivors I  
interviewed as breast cancer became a reality for you at a young age,  
your friendship I cherish.

## **Acknowledgements**

It truly takes a village to raise a doctorate nurse.

I am extremely grateful for the support I received during my studies  
both formal and informal.

To Louise, thank you for seeing beyond a mediocre GPA and CV with one semester of teaching experience. Thank you for giving me a chance, I hope I have made you proud. Thank you for being my mentor as an advanced practice nurse, researcher and educator; you were one of my biggest strengths and your wisdom infinite.

To Susie and Faye, you provided me with childcare and household support throughout my doctoral studies. This allowed me peace of mind. This meant the world to me.

To my professional family at SUNYIT, thank you for allowing me the time to complete my study and for stepping up to the plate when I was on leave. I will never forget this opportunity you afforded me.

To Zoey, who accompanied me into the late hours every night and never left my side.

To Karen Christenson and the After Breast Cancer Support Group, I am thankful for the opportunity to work with this community resource and especially grateful to have met

Karen as she is truly a dedicated community leader.

To Dr. Lev, thank you for the emails prodding me along, the meetings at the Bedford library and the constructive criticism. I appreciate the guidance and mentorship throughout this process.

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## Negotiating Emotional Order: A Grounded Theory of the Survivorship Process in Women Who Have Completed Treatment for Breast Cancer

Nurses concerns about the psychosocial ramifications of chronic illness have a long history. Florence Nightingale recognized the psychosocial aspects of patient care in her seminal writing, *Notes on Nursing: What it is and what it is not*. “Apprehension, uncertainty, waiting, expectation, fear of surprise, do a patient more harm than any exertion” (p.25, Nightingale, 1859/2003). Nightingale wrote of the importance of nurses addressing the psychosocial aspects of illness in 1859, and in modern times survivorship care continues to be of great importance in nursing care. The Institute of Medicine resonated the same concern about psychosocial hindrances with regard to cancer patients, citing them as a critical area needing improvement within the nation’s healthcare system (Hewitt, Greenfield & Stovall, 2005; Institute of Medicine, 2009). With increasing numbers of breast cancer survivors, the process of breast cancer survivorship needs to be fully understood by nurses and health care providers (HCPs) in order to attain optimal health outcomes for this ever growing population.

### **Population of Concern: Breast Cancer Survivors**

The word "survive" means to “live beyond” and is derived from the Latin word *supervivere* (Traupman, 2007). The number of women who survive after the diagnosis of breast cancer has increased dramatically (Hayat, Howlander, Reichman, & Edwards, 2007; Jemal et al., 2008; McCloskey, Lee, & Steinberg, 2011; NCI, 2010; O’Shaughnessy, 2005; Petraca et al., 2011 Slamon et al., 2011). According to Jemal et al (2008), 88% of women diagnosed with breast cancer will survive more than five years.

The National Cancer Institute (NCI), reported breast cancer is the second leading cause of malignancy in women worldwide, and it was estimated in 2007 that there were 2.6 million women living in the United States with a history of breast cancer (NCI, 2010). The incidence of breast cancer inclusive of all races in the United States is 122.9 per 100,000 women (NCI, 2010). Breast cancer has an economic impact of \$13.9 billion annually on the strained national economy (National Cancer Institute, NIH, & DHHS, 2010).

According to the National Cancer Institute (NCI) each year 207,090 women in the U.S. will be diagnosed with breast cancer, and approximately 40,000 will succumb to the disease (NCI, 2010). Beyond the mortality of breast cancer, there is a rising population of women who are breast cancer survivors. In 2011, it was reported that there were 2.6 million survived breast cancer survivors living in the United States (Breastcancer.org, 2012).

For this study, the National Coalition for Cancer Survivorship (NCCS) definition of survivor will be used. A survivor will be defined as a woman diagnosed with breast cancer until the end of her life (Hewitt et al, 2005; NCCS, 1986). As the population of breast cancer survivors grows and lives longer, the care of extended breast cancer survivors will become increasingly prominent in health care settings. Thus the nursing profession must heighten its awareness of this population.

Extensive research regarding cancer treatment has promoted better outcomes in treating the disease, yet there is a significant gap in the literature regarding the survivorship process (Hayat, Howlander, Reichman, & Edwards, 2007; McCloskey, Lee,

& Steinberg, 2011; Meissner et al., 2011; O'Shaughnessy, 2005; Petraca et al., 2011 Slamon et al., 2011). Global and national efforts have been used to battle breast cancer and great strides have been made as evidenced by increasing survivor rates (Hayat, Howlander, Reichman, & Edwards, 2007; McCloskey, Lee, & Steinberg, 2011; Meissner et al., 2011; O'Shaughnessy, 2005; Petraca et al., 2011 Slamon et al., 2011).

### **The Concern to be Addressed**

The concern addressed in this study is the need for greater understanding of the process of transitional survivorship from the perspective of women who have completed initial treatment for breast cancer. Transitional survivorship is defined as the timeframe that immediately follows the completion of treatment for cancer prior to the cancer survivor entering into extended survivorship (Miller, Merry & Miller, 2008). There is a significant opportunity from the perspective of the breast cancer survivor to define and explore the challenges survivors endure as they move from transitional into extended survivorship.

Empirical evidence from breast cancer survivors has revealed that there are gaps in treatment and the diverse needs of cancer survivors often go unmet. (Armes et al., 2009; Harrison et al., 2010; Mao et al., 2009). As the patient population of breast cancer survivors is increasing, and the Institute of Medicine report has prioritized survivorship care, it is imperative for the healthcare community to understand the process of survivorship from the perspective of the women who are in the midst of this lifelong process.

### **Phenomenon of Interest: Breast Cancer Survivorship**

The phenomenon of interest in this study is transitional survivorship in women with breast cancer. Survivorship is a “dynamic, life-long process” that starts once a woman is diagnosed with breast cancer (Pelusi, 1997, p. 24). The stages of cancer survivorship were initially discussed in the mid 1980’s; thirty years later, the stages have been further expanded to reflect the positive impact of technology and treatment methods that have increased longevity in this population (Miller et al., 2008; Miller, 2010; Mullan, 1985). In this study, transitional survivorship will be defined the process occurring after a woman completes initial treatment for breast cancer as she enters into extended survivorship (Miller et al., 2008, Miller, 2010).

Survivorship is a phenomenon of importance to cancer patients. Much of the research on this topic is based on a single, subjective narrative introduced by Mullan (1985). Survivorship has been acknowledged as a phenomenon experienced by women diagnosed with breast cancer, but the concept of survivorship has not been fully explored (Doyle, 2008; Pelusi, 1997). Little is known about the processes breast cancer survivors use to maneuver through the health care system and how survivors maintain mental and physical health after being successfully discharged by the oncologist.

In the time period after the woman is released from acute and adjuvant care of the oncologist, women must subjectively evaluate courses of action to maximize their health. Although patient education, treatment guidelines and survivorship groups are available to women with breast cancer, the woman must individually decide how to optimize her health based on her own physical and mental health needs. The patient’s perception of



her needs may be different than the healthcare provider's perceptions. In many cases, the healthcare provider may not recognize this personal struggle. As a result, many survivors conform to the provider's suggestions opting not to oppose the provider and endure a struggle alone (Arman & Rehnsfeldt, 2003).

### **Purpose of Research**

The purpose of this research was to conduct a Glaserian style, qualitative study using a construct oriented approach to generate grounded theory, to explore the transition process of women with breast cancer as they enter extended survivorship (Glaser, 1998). The focus of this study was to investigate the process of transitional survivorship in women who have completed initial treatment for breast cancer. This study explored the dynamic process of survivorship and will aid in defining the psychosocial challenges women experience once they have completed breast cancer treatment and enter extended survivorship.

According to Meleis and associates (2000), transition is a constant and central concept in nursing practice. Staff nurses and advanced practice nurses support, educate, and offer encouragement to each breast cancer survivor through their transition (Lobb et al., 2009; Rancour, 2008). However this support is based on nurses' empathetic responses rather than on empirical research. Few theory based interventions for counseling women with breast cancer currently exist (Lev & Owen, 2000).

### **Foundational Assumptions**

Historically, breast cancer survivorship has often been viewed simply as evidence of a past medical diagnosis or a label (Doyle, 2008). Pelusi (1997) describes breast cancer

survivorship as the phenomena present in women diagnosed with breast cancer. Evidence suggests that women who have completed initial treatment for breast cancer endure a complex, multifaceted process that lasts until the end of their lives.

Evidence suggests that unmet needs and psychological distress may be hindering the optimal health and well-being of breast cancer survivors. It is known that women who have completed initial treatment for breast cancer often have unmet needs in information, physical symptoms, communication, and psychological distress areas (Armes et al., 2009; Harrison et al., 2011; Mao et al., 2009; McDowell et al., 2010; Sanson-Fisher et al., 2000). Because of a lack of research on the topic of breast cancer survivorship, the documented unmet needs may only be a part of this complex process. Other aspects of this process may be concealed. In addition, breast cancer survivors feel alone in their experience, abandoned by the healthcare community, and frequently struggle in private (Davies & Sque, 2002; Jefford et al., 2008; Rosedale, 2009; Rosedale & Fu, 2010).

### **Summary**

It is important that nurses and primary care providers (PCPs) deliver quality, holistic care, as they are the healthcare providers most frequently responsible for rendering health care once acute and adjuvant treatment for breast cancer ends (Snyder et al., 2009). With the changing health arena in the United States, it is imperative PCPs provide quality care to this growing population. This study used grounded theory method (GTM) to explore the perspective and panorama of the transition of women that have completed treatment for breast cancer into extended survivorship.

## **CHAPTER II.**

### **Literature Review**

Breast cancer is an ancient disease with current implications. The Egyptians first documented breast disorders on papyrus in 1500 B.C., followed by Hippocrates, Celsus and Galen (Harding, 2007; Olsen, 2003). It was not until 1666 that definitive evidence of breast cancer was documented with the death of Queen Anne of Austria. Breast cancer trends were first noted in the epidemiological literature of the late 19<sup>th</sup> century, but until the 1970's, breast cancer trends were presented only in medical journals (Harding, 2007). This is not the case today, as breast cancer data is present in both the popular and empirical literature.

#### **Purpose of a Literature Review in Grounded Theory Qualitative Inquiry**

There are conflicting arguments regarding the necessity of performing a literature review in qualitative inquiry. Glaser (1978, 1992, 2008, 2011) postulates that in grounded theory a preliminary literature review is unnecessary as literature will exist regardless of additional studies and will potentially produce biased results. Glaser (1978, 1992, 1998, 2008, and 2011) also suggests that literature should be reviewed once theory emerges to assist saturation, tightening, and sorting the data collected. Alternatively, in later publications (1998, 2011), Glaser has advocated for an early literature review to put the prospective study into proper context, and to sensitize the researcher. A thorough literature review is also mandated by academic authorities and funding agencies prior to research commencement.

Other qualitative researchers have asserted that an a priori review of the literature will assist the research in developing a foundational understanding of the research topic, and identify gaps of research opportunity within current publications prior to commencement of research (Hallberg, 2010). It has also been postulated that a researcher's previous knowledge, and/or use of the literature, will not hinder the induction of theory (McGhee, Marland, & Atkinson, 2007).

For this literature review, a foundational search was conducted to explore the existing empirical research and identify gaps of information and/or unanswered questions. Drawing from the literature review, the researcher identified opportunities and targeted literature to frame the study direction. To initially sensitize the writer, current, relevant articles were accessed using the State University of New York Institute of Technology, Cayan Library electronic database and the Rutgers Dana Library electronic library databases. PubMed, CINAHL, PyscINFO and Medline and EBSCO catalog host were the primary database engines searched. Search terms including: 'breast carcinoma', 'breast cancer', 'cancer survivor', 'cancer survivorship', and 'breast cancer survivor' were entered into the filter. In addition the words: 'survivor', 'survivorship', 'long term survivorship', and 'transitional survivorship', 'treatment', and 'primary care' were added to the primary terms to augment the literature search

Current literature was reviewed as suggested by Galvan's (2006) recommendations for literature review. Journal articles from the scholarly disciplines and popular literature were reviewed. The search was supplemented by Google Scholar, and articles were retrieved from the websites of the Institute of Medicine, American Cancer Society, PubMed, and National Cancer Institute. The review was generally limited to

sources dated from 2006 -2011, but literature published prior to these dates was also reviewed for historical purposes. Once the studies were identified and located, the articles were sorted. After sorting and a review of relevance, the manuscripts were summarized with regard to: research methods, population demographics, definitions of key terms, and research results (Appendix A).

### **Evolution of the Concept of Survivorship**

The limited availability of historical literature on cancer survivorship in general and breast cancer survivorship in particular supports the need for qualitative investigation. Although survivorship is not a new concept, cancer survivorship is a contemporary reality. Enhanced screening and treatment modalities have produced a rising population of breast cancer survivors (National Cancer Institute, 2010). The concept of survivorship defines a process. Survivorship is an emerging, yet immature concept, without a theoretical framework (Doyle, 2008). Grounded theory investigation may help advance the explication of the process of breast cancer survivorship from a theoretical standpoint.

The concept of survivorship was initially associated in the literature with wartime strife, which is exemplified by Viktor Frankl's seminal work, published initially in 1946, describing his experience of surviving imprisonment in Nazi concentration camps. Later survivorship emerged in the medical literature to describe life after a myocardial infarction (Lew, 1967). During the 1980's, published articles concerning the topic focused on survivorship solely as a biomedical process measured in five year increments

(Shanfield, 1980). The historical medical definition of cancer survivorship was a person who lived five years after the diagnosis of cancer (Shanfield, 1980).

### **Stages of Survivorship Defined**

The concept of cancer survivorship changed dramatically in the 1980s as more cancers were diagnosed and treated successfully. With these improvements, cancer survivors who lived more than five years became prevalent (Doyle, 2008, Odle, 2011). Mullan (1985) published a seminal article, a subjective narrative, which describes his lung cancer survivorship as a dynamic process that lasts from diagnosis to the time period beyond treatment. Shortly after this article was published in the *New England Journal of Medicine*, Mullan co-founded the National Coalition for Cancer Survivorship (NCCS) (Doyle, 2008). The NCCS was formed in response to the increasing numbers of survivors nationally. The NCCS adopted Mullan's definition of cancer survivorship (Doyle, 2008, Odle, 2011). In the proposed study, breast cancer survivorship will be broadly defined as the process a person experiences from the moment of diagnosis until the end of their life (NCCS, 1986).

There are three stages in the survivorship process, as proposed by Mullan (1985): acute, extended, and permanent. The antecedent of cancer survival is a diagnosis of cancer (Doyle, 2008). The acute stage of survivorship begins at diagnosis and ends with the termination of initial and adjuvant treatments (Mullen, 1985; Lance Armstrong Foundation & Center For Disease Control, 2004). The acute stage encompasses treatment modalities and their side effects (Mullen, 1985). Mullen (1985) postulated the extended stage of survivorship begins when initial cancer treatment ends and/or the disease

successfully enters remission (Mullan, 1985). Permanent cancer survivorship begins once the individual is considered cancer free and is able to successfully return to their pre-cancer baseline physically and emotionally (Langlands, Pocock, Kerr, & Gore, 1979; Mullan, 1985).

Interestingly, Mullan's subjective narrative has become the staple in cancer survivorship literature. The author of this narrative is 32 year male who is himself a lung cancer survivor. This fact in itself would normally cause this seminal work to be potentially biased and render the proposed stages of survivorship non-generalizable to the population of cancer survivors. To date, Mullan's proposed stages of survivorship can be found referenced in multiple credible authorities' web page and publications (Center For Disease Control, 2012; Dana-Farber Cancer Institute, 2012; Hewitt, Greenfeild & Stovall, 2005; U.S. Department of Health And Human Services, 2012). To date, no studies have been conducted among breast cancer survivors which test the theoretical propositions Mullan identified.

### **Breast Cancer Survivors Evolve**

Almost thirty years have passed since the NCCS charter was written and Dr. Mullan's seminal work was published (Mullan, 1985; NCCS, 1986). Since then, survivorship has lengthened and overall cancer-related mortality has decreased due to early detection and improved treatment modalities (National Cancer Institute, 2010). Today, the diagnosis of breast cancer tends to occur at an earlier stage due to improved screening methods and technology (Houssami & Ciatto, 2011; Meissner, Klabunde, Han, Benard, & Breen, 2011; Warner, 2011). The use of radiation and chemotherapy have

improved survival in breast cancer (McCloskey, Lee, & Steinberg, 2011; Slamon et al., 2011). The use of tailored biologic and targeted therapies for breast cancer has also improved the prognosis and has increased the chances of remission or cure (O'Shaughnessy, 2005; Petraca et al., 2011).

Because of the significant increase in patients who are now living with breast cancer as a chronic disease, the conceptualization of cancer has changed in some cases from that of a terminal illness to that of a manageable chronic illness (Allen, Savadatti, & Levy, 2009; McCann, Illingworth, Wengström, Hubbard, & Kearney, 2010). Inasmuch as patients may have not only years but decades of long term survivorship, they are now more likely to experience normal issues of aging that may have additional sequelae due to the long term effects of cancer or cancer treatment (Allen, Savadatti, & Levy, 2009; Foley et al., 2006). Additionally, cancer patients may develop primary cancer recurrence or develop secondary cancers related to chemotherapy or radiation therapy (Karam, 2011).

### **The Process of Survivorship Revisited-Assertions**

The stages of survivorship introduced initially by Mullan in 1985 were revisited by Miller, Merry, and Miller (2008). Miller et al. expanded on the initial model of cancer survivorship by exploring the current population of cancer survivors and considering the transformation of the population over the past twenty years (Miller et al., 2008). The authors asserted changes to Mullan's initial model were needed based on personal clinical experience with cancer survivors rather than through formal empirical research.



The acute stage of survivorship did not significantly change in the new model. Acute survivorship begins at diagnosis and ends with the termination of initial treatment. Miller et al. (2008) did modify the existing model, introducing the concept of transitional survivorship, in addition to further expanding the concepts of extended survivorship and permanent survivorship to reflect the heterogeneous nature of cancer survivors.

Miller et al. (2008, 2010) suggest that transitional survivorship begins once treatment has ended and during the time the individual is transitioning from patient into extended survivorship time period. Although a positive milestone, survivors in the transitional stage also report this as a time of psychological distress (Miller, 2010; Rosedale, 2009; Rosedale & Fu, 2010). During the time frame of transitional survivorship, the survivor's experience with cancer becomes reality and they transition back into a life that does not involve cancer treatment, often having less contact with oncology healthcare providers (Lobb et al., 2009; Miller et.al., 2008).

In the new model, Miller (2010) proposes further dividing extended survivorship into three patient groups based on medical characteristics: 1) individuals free of cancer; 2) individuals living with cancer as a chronic disease, and 3) those individuals in remission because of ongoing treatment (Miller, 2010). For those who achieve extended survivorship and are cancer free, the permanent survivor stage was further expanded to include different types of permanent survivorship (Miller et al., 2008, Miller, 2010). Permanent survivorship includes: 1) survivors who are cancer free, and free of cancer physical and psychological sequelae; 2) survivors who are cancer free, but not free of initial cancer related physical and psychological sequelae; 3) survivors diagnosed with a second type of cancer; and 4) permanent survivors diagnosed with cancers secondary to

the initial cancer treatment (Meyerowitz, Kurita, & D'Orazio, 2008; Miller et al., 2008, Miller, 2010; Naus, Ishier, Parrott, & Kovacs, 2009).

Allen, Savadatti & Levy (2009) explored transitional survivorship in breast cancer survivors who had completed initial treatment within the 12 months prior to their study. The women were age 35 to 86 years, with a mean of 57 years. Utilizing focus group interviews with 47 women, Allen and associates (2009) analyzed the transcripts outlined by Strauss and Corbin with constant comparative analysis. The authors reported that the period of time when a woman transitions into life without treatment has numerous psychological and physical challenges. Themes reported by the authors included: 1) positive life changes as result of the cancer experience; 2) fear of recurrence; 3) emotional distress; and 4) losses associated with the end of treatment and difficulty returning to 'normal' life. These findings did shed some light upon issues related to transitional survivorship among breast cancer survivors. However, the reported findings cannot be generalized to the entire population of breast cancer survivors (Webb & Kevern, 2001). It is likely that focus groups may not have captured the individual's experience of breast cancer survivorship. Additionally, the authors did not comment on group interaction, which is central to the effectiveness of focus groups, nor is there mention of participant validation of the research findings (Webb & Kevern, 2001).

### **Further Expansion of Mullan's Original Survivorship Model**

Galvan, Buki, and Garces (2009) conducted focus group interviews to explore the emotional, informational, and instrumental support needs of 22 immigrant Latina women, mean age 51 years, who were diagnosed with breast cancer. Galvan et al. (2009) used the

following time frames to sort the participants into support groups: acute (0-1 year post diagnosis), reentry (1-3 years post diagnosis), and long-term survivorship (4 or more years post diagnosis). Galvan et al. (2009) hypothesized that dividing the participants into groups based on Mullan's typology (1985) may reveal that support needs change as the survivor moves through the stages of survivorship.

This study identified three stages of survivorship: diagnosis, treatment, and after treatment. These stages differed from Mullan's (1985) original concept, where the acute stage encompassed both diagnosis and treatment (Galvan et al., 2009). In the Galvan et al. (2009) study, the women reported different needs during diagnosis and treatment, raising the possibility that Mullan's original conceptualization may mask important distinctions in the breast cancer survivorship process, and that the acute stage of survivorship needs further exploration. This study did support the fact of the presence of the process of survivorship among women who have been diagnosed with breast cancer.

Little detail was given by Galvan et al. (2009) of the substantive research project and data analysis methods that they used. It was unclear what methodology was utilized in this study. Galvan et al. (2009) authors spoke of focus groups but did not reference primary sources defining focus groups. They did however cite Denzin and Lincoln (2001) in the methods section. Focus group interviews are designed to explore attitudes and perceptions related to concepts in part by interaction with other people (Krueger, 1994,; Webb & Kevem, 2001). There was no mention of interaction of the individuals who participated in the focus groups in the data analysis or results. Additionally, two single interviews were used in the analysis. Thus the primary reason of using focus groups was not employed (Webb & Kevem, 2001).

In another focus group study, Buki et al. (2008) interviewed Latina breast cancer survivors about their experiences throughout the survivorship continuum. The breast cancer survivors were divided into groups according to Mullen's conceptualization: acute, extended, and permanent. Buki et al. (2008) identified five different experiences during the survivorship continuum: 1) perceptions of psychological well-being; 2) need for social support; 3) impact of well-being; 4) treatment effects on well-being and 5) attitude development. Buki et al. (2008) noted that perceptions of psychological well-being and the need for social support were present in all of the stages of survivorship. The experience of impact on well-being was present only in the acute stage, whereas treatment effects on well-being and new attitude development were present in both the extended and permanent stages of survivorship. This study exemplified the fact that the stages of survivorship exist in the population of breast cancer survivors and that the needs of breast cancer survivors may be different depending on the stage of the survivorship continuum.

Galvan et al. (2009) reported that the data were analyzed using Strauss and Corbin's (1998) method. The authors did not mention having used concurrent data generation and analysis as would be required in grounded theory. Additionally there is no mention of constant comparative analysis as additional data were collected. It is clear that, if several focus groups are conducted in a similar way and then the transcripts are subjected to a grounded theory type of analysis, this description alone does not meet criteria for grounded theory (Hunter et al., 2011). Additionally, it seems that data analysis was conducted following rather than concurrently with data collection. The technique cannot then legitimately be classified as grounded theory, because the essence of the

method is that it is cumulative. Strauss and Corbin themselves explain each event sampled builds from and adds to previous data collection and analysis. Moreover, sampling becomes more specific with time because the analyst is directed by the evolving theory (Strauss & Corbin 1998, p. 203).

Both studies that used Mullan's (1985) conceptualization were conducted among Latina breast cancer survivors using focus groups, so the results may not be applicable to the general population (Buki et al., 2008; Galvan, Buki & Garces, 2009, Webb & Kevem, 2001). It should be noted that Mullan's (1985) conceptualization was used only to sort the participants and that the actual process of survivorship was not explored. Further understanding of the process of breast cancer survivorship may impact patient care of breast cancer survivors by identifying the stages of survivorship that are unique to this population. This is especially significant as the survivorship paradigm is evolving, moving beyond only the treatment aspects of cancer treatment and proving that breast cancer survivorship is an understudied process in an evolving population.

### **Phenomenon of Survivorship Identified in Women Diagnosed with Breast Cancer**

Pelusi (1997) identified the survivorship phenomenon from the perspective of women with breast cancer. Pelusi conducted a phenomenological study among eight breast cancer survivors, ages 34-70 years, who had completed treatment for breast cancer. In this study, transition from patient to survivor was a theme identified by the women. During the interviews, the women identified the time period immediately after they completed their initial treatment for breast cancer as the crucial period in their experience of transitional survivorship. During this time, the women reported feelings of

abandonment, uncertainty, fear of recurrence, loneliness, and self-transcendence (Pelusi, 1997).

Once the women in Pelusi's study (1997) were healthy enough to return to the care of their PCP, they identified a number of concerns. First, the women noted feeling abandoned by the oncology team, who they had envisioned would manage their medical care for the rest of their lives. The women identified their oncology health care providers as sanctuaries providing security, comfort, and hope during active treatment and after treatment (Pelusi, 1997). Second, the women noted a conflict between their own expectations of follow up and the reality of follow up care after initial treatment for breast cancer (Pelusi, 1997). Social components identified as part of the survivorship process included: 1) financial resolution; 2) increased health practices; 3) mediating the expectations of social circles; and 4) helping others. All were seen as important aspects of the survivorship experience (Pelusi, 1997). Pelusi's work shed crucial light on the experience of surviving breast cancer from survivors' voices and identified this phenomenon among women diagnosed with breast cancer.

Pelusi (1997) attempted to address gaps in the literature by identifying breast cancer survivorship as a phenomenon unique to the population of interest. Pelusi (1997) used a phenomenological research design and used methodological keywords such as: experience, bracketing, and phenomena (Norlyk & Harder, 2010). The purpose of this study was to understand the phenomena of survivorship in the increasing population of breast cancer survivors (Ryan, Coughlan & Cronin, 2007). Pelusi (1997) followed and described the analysis process according to Colaizzi's (1978) method. Consistent with the dependability of phenomenological methods, Pelusi stressed the importance of

openness and used bracketing as well as an outside review of the data. (Norlyk & Harder, 2010, Ryan, Coughlan & Cronin, 2007). Pelusi (1997) further validated the data with the participants.

Phenomenology research methods and grounded theory are two of the most basic qualitative research designs used to describe the experiences of a distinct population (Patton, 2002). Although an exhaustive literature review was conducted, no grounded theory inquiry was found on the process of breast cancer survivorship. Therefore this study builds upon Pelusi's phenomenological study on survivorship in women who have been treated for breast cancer by using grounded theory to describe and explain the process of breast cancer survivorship.

### **Current Survivorship Initiatives**

Survivorship initiatives are a current national priority. In the United States, initiatives addressing cancer survivorship are found in *Healthy People 2020* and the consensus report, jointly published by the NCI and IOM, titled *From Cancer Patient to Survivor: Lost in Transition* (Hewitt, Greenfield & Stovall, 2005). Cancer survivorship was included in *Healthy People 2020* in objectives C-13 and C-14 (U.S. Department of Health And Human Services, 2012). Objective C-13 sets a priority to increase the proportion of cancer survivors who are living five years or longer after initial diagnosis. The objective C-14, "Increase the mental and physical health-related quality of life of cancer survivors", specifically targets the cancer survivorship process that will be addressed and is a goal in this study.

Hewitt and colleagues (2005) addressed survivorship issues and the immature status of cancer survivor research, while calling for greater research and attention to the population of cancer survivors. Cancer survivorship research is exigent, as latent physical and psychological effects may not emerge for decades, thus requiring lengthy periods of researcher and participant engagement (Ganz, 2003). This report also concluded there are many issues cancer survivors endure, specifically during the transition into primary care once cancer treatment has been completed. Four initiatives recommended in this report for future research support the need for a qualitative analysis including research needed to understand “1. Mechanisms of late effects experienced by cancer survivors, 2. How to identify and intervene to alleviate symptoms and improve function, 3. The prevalence and risk of late effects, 4. Survivors’ and caregivers’ attitudes and preferences regarding outcomes and survivorship care” (p. 497, Hewitt, Greenfield & Stovall, 2005).

### **Current Literature**

Consensus is found in the literature, as authors unanimously agreed that survivorship begins with diagnosis and does not end until death (Miller et al., 2008; Mullan, 1985, NCCS, 1985; Pelusi, 1997). Despite a large body of research existing on breast cancer survivorship, no study was located that examined the process of survivorship from the perspective of women who have been diagnosed with breast cancer. Although much of the literature referenced Mullan’s (1985) subjective narrative describing stages of survivorship, these stages have not been formally tested.



### **Un-met Needs**

Much of the literature that was found did not focus on the stages of survivorship; however other unmet needs were reported. A chart of the literature review was constructed (addendum A). In a majority of the studies themes of un-met needs included physical needs, support, psychological, communication, information, health system and fear of recurrence (Aranda et al., 2005; Bowman et al., 2010; Coggin & Shaw-Perry, 2006; Harrison et al., 2011; Jefford et al., 2008; Lobb et al., 2009; McDowell et al., 2010; Sanson-Fisher et al., 2000).

Un-met needs are present in breast cancer survivorship; however the unmet needs have not been associated with specific stages of breast cancer survivorship. Multiple unmet needs were identified by many researchers using surveys (Aranda et al., 2005; Bowman et al., 2010; Coggin & Shaw-Perry, 2006; Harrison et al., 2011; Jefford et al., 2008; Lobb et al., 2009; McDowell et al., 2010; Sanson-Fisher et al., 2000). One of the studies that addressed un-met needs used focus groups (Jefford et al., 2008). Of the studies reviewed only two were specific to breast cancer survivors (Coggin & Shaw-Perry, 2006; Aranda et al., 2005). The remainder of the studies focused on several different types of malignancies and included health care professionals among the sample participants (Bowman et al., 2010; Harrison et al., 2011; Jefford et al., 2008; Lobb et al., 2009; McDowell et al., 2010; Sanson-Fisher et al., 2000).

Unmet needs also were found to be present over time, not just during one time frame during breast cancer survivorship. In two of the studies, unmet needs were reported initially and then again in six months (Armes et al., 2009; McDowell et al., 2010). Armes

et al. (2009) reported 30% of patients had more than five unmet needs at baseline, and for 60% of these patients, the situation did not improve. Unmet needs were reported by approximately two-thirds of patients at baseline and half of patients at six months follow-up (McDowell et al., 2010). Length of time since diagnosis was a consistent positive predictor of greater unmet needs, associated with change in physical/daily living, psychological and health system and information unmet needs over time (McDowell et al., 2010). This indicated that unmet needs continue to be an issue that continues over time and psychological needs may emerge later in the survivorship process.

In addition to the common themes in the findings, commonalities were found among the results of studies that addressed un-met needs of cancer survivors. All of the studies that were reviewed that explored unmet needs used survey methods (Aranda et al., 2005; Bowman et al., 2010; Coggin & Shaw-Perry, 2006; Harrison et al., 2011; Jefford et al., 2008; Lobb et al., 2009; McDowell et al., 2010; Sanson-Fisher et al., 2000). Although helpful to aid to describe characteristics of individual groups, surveys are thought to have decreased internal validity and decrease variety and individuality (Carr, 1994; Ho, Petersons, & Masoudi, 2008; Walker, 2005). Additionally this research method may not capture the holistic essence of breast cancer survivorship.

Of these aforementioned studies, only two were exclusive to breast cancer survivors (Aranda et al., 2009; Coggin & Shaw-Perry, 2006). In the rest of the studies, breast cancer survivors comprised 32% to 57% of the participants (Armes et al., 2009; Harrison et al., 2011; McDowell et al., 2010; Sanson-Fisher et al., 2000). A methodological weakness was found in the use of the Supportive Care Needs Survey that was used in three studies (Aranda et al., 2005; McDowell et al., 2010; Sanson-Fisher et

al., 2000). This tool was developed and validated among cancer patients who were in active treatment for cancer, and 32 % of the cancer patients in this group had breast cancer (Bonevski et al., 2000). In the Aranda et al. (2005) study the mean time since diagnosis was 5 years and in the McDowell et al. (2010) study 78% of the participants had completed treatment, so the Supportive Care Needs Survey may not have been the most appropriate tool for these stages of survivorship.

Additionally, Aranda et al. (2005) used this measure in a population of only breast cancer survivors. Again, the Supportive Care Needs Survey may have not been the best tool as it may not capture the needs of breast cancer survivors. Sanson-Fisher et al. (2000) did use this tool with patients during active treatment for cancer; this is not surprising as Sanson-Fisher was an author of this measurement tool (Sanson-Fisher et al., 2000, Bonevski et al., 2000).

### **Psychological Distress**

Psychological symptoms are often hard to quantify, yet are an important component of extended survivor treatment. The National Comprehensive Cancer Network (2008) has defined distress as, “a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social and or spiritual nature that may interfere with the survivor’s ability to cope”. Breast cancer survivors have been found to have continued psychological distress after treatment ends (Aranda et al., 2005; Costanzo et al., 2007; Doumit et al., 2010; Knobf, 2007; Rosedale, 2009, Wilkins & Woodgate, 2011).

Several studies in the literature review addressed the themes of psychological distress (Beatty et al., 2008; Doumit et al., 2010; Henselmans et al., 2008; Lebel, Roserberger, Edgar & Devins, 2007; Mallinger, Grigs & Sheilds, 2006; Rosedale, 2009; Wilkins & Woodgate, 2011). Despite three different research approaches: questionnaire, phenomenology, and focus groups, all of the studies linked distress during breast cancer survivorship with stress and readjustment (Beatty et al., 2008; Doumit et al., 2010; Henselmans et al., 2010; Lebel, Roserberger, Edgar & Devins, 2007; Mallinger, Grigs & Sheilds, 2006; Rosedale, 2009; Wilkins & Woodgate, 2011).

Beatty et al. (2008) explored the psychological needs of breast cancer survivors using focus groups of breast cancer survivors, as well as oncology nurses and volunteers who work with breast cancer survivors. Six major themes were found: 1) coping with side effects; 2) self-concept change; 3) physical, personal and social aspects; 4) stress and adjustment related to diagnosis, treatment and treatment completion; 5) managing others and 6) survival (Beatty et al., 2008). Another aspect of psychological distress reported was anxiety and depression related to birthdays and anniversaries of treatment milestones (Beatty et al., 2008). Beatty et al. (2008) reported that the women expressed psychological distress from lack of closure as treatment was completed, and from the knowledge that the cancer may return (Beatty et al., 2008). The breast cancer survivors identified fear of recurrence as well as the need to come to terms with their own mortality both of which created on-going psychological distress (Beatty et al., 2008). The authors did not identify a specific method for coding the data but did utilize emergent themes and note group interaction. Since study subjects included oncology nurses as well as volunteers, the findings are not solely from the perspective of the breast cancer survivors.

Henselmans et al. (2010) used the General Health Questionnaire to explore psychological distress in 171 breast cancer survivors during the first years after diagnosis. Henselmans et al. (2010) reported that 63.7% of the breast cancer survivors experienced distress during the first year after diagnosis. Ongoing stress and distress in the reentry and survivorship stage was present in 30.4% of the participants (Henselmans et al., 2010). This was consistent with Beatty et al. (2008) who reported participants expressed feelings of isolation which intensified after treatment completion and a sense of abandonment by medical and healthcare personnel. The General Health Questionnaire is not a breast cancer specific tool so these findings may be non-specific to the group surveyed.

Doumit et al. (2010) conducted a phenomenological study to explore coping with breast cancer among 10 Lebanese women. Doumit et al. (2010) identified several factors that appeared to facilitate coping. The authors noted that all of the participants regardless of religious background viewed cancer as an act of God; viewed cancer as similar to other diseases, mainly diabetes; and valued family support and sharing their experience with people who have also had breast cancer (Doumit et al., 2010). In this study, it was found that factors which hindered coping included altered body image, fear of recurrence, and a sense of being pitied by others.

It is known that breast cancer survivorship is not a static experience, but rather a phenomenon that occurs from diagnosis to death (Pelusi, 1997). Phenomenological methods do not explain experiences, but instead focus on rich description during a particular time frame (Ryan et al., 2007). A drawback to this qualitative approach is that information about broader periods surrounding the origin, factors associated with the phenomenon and consequences of the experience may be missed (Norlyk & Harder,

2010; Ryan et al., 2007). A methodological weakness in Doumit and associates' study was the fact that the survivors were interviewed at different time periods, ranging from 4 months to 9 years after diagnosis.

Mallinger, Griggs & Shields (2006) conducted a cross sectional survey of 234 breast cancer survivors to explore the association between open family communication and breast cancer survivor psychological health. The authors used the Family Avoidance of Communication about Cancer Scale and the Medical Outcomes Study Short Form, neither of which are breast cancer survivor specific. Mallinger et al.(2006) reported that avoidance and mental health were negatively correlated in bivariate as well as multivariate analysis. This study confirmed that emotional support is associated with positive psychological well-being.

Rosedale (2009) conducted a phenomenological study with a purposeful sample of 13 women following breast cancer treatment to explore survivor loneliness after breast cancer treatment. The breast cancer survivors in this study described the fundamental qualities associated with loneliness, including an emerging consciousness, transcending time, misunderstanding, inauthentic mirroring, fragile vital connections, and withholding truth (Rosedale, 2009). Emerging consciousness occurred when the breast cancer survivor: 1) felt alone in her experience; 2) when she became aware that others were not aware or able to comprehend what it was like to survive breast cancer treatment; or 3) recognize the long term psychological sequelae of breast cancer (Rosedale, 2009). Rosedale (2009) reported that many of the breast cancer survivors experienced loneliness when they transitioned into extended survivorship, because they felt their healthcare providers, family and friends did not understand the phenomenon they were

experiencing. Fear of recurrence is a stressful aspect that survivors battle from the time of diagnosis until the end of their lives (Bower et al., 2005; Doumit, Huijjer, Kelley, Saghir, & Nassar, 2010; Lebel, Rosberger, Edgar, & Devins, 2009; Sadler-Gerhardt, Reynolds, Britton, and Kruse, 2010). Fear of recurrence was a theme that was found in much of the literature that was reviewed (Allen, Savadatti & Levi, 2009; Armes et al., 2009; Beatty et al., 2008; Harrison et al., 2011; Lebel, Roseberger, & Devins, 2007; Sadler-Gerhardt, 2010; Sanson-Fisher et al., 2000; Wilkins & Woodgate, 2011).

Lebel, Roseberger, and Devins (2007) conducted a longitudinal study to investigate the degree of stress caused by cancer concerns: fear of recurrence, physical limitations, pain, and problems with families and friends in breast cancer survivors. Lebel et al. (2007) used an adapted version of the Ways of Coping Questionnaire-Cancer Version with 72 newly diagnosed breast cancer survivors. The Ways of Coping Questionnaire-Cancer Version is designed for breast cancer survivors and measures the thoughts and actions used to cope with cancer related concerns. The measure to be used in the study was derived from this tool but the reliability and validity of the version proposed for this study was not reported. Cancer concerns, with the exception of the fear of recurrence, were not appraised as stressful (Lebel et al., 2007). Fear of cancer recurrence was found to be the most troubling emotional concern, present throughout the cancer survivor continuum (Lebel et al., 2007). Fear of cancer recurrence was found as early as three months up to six years post-diagnosis (Lebel et al., 2007).

Wilkins and Woodgate (2011) explored how cancer survivors define and interpret second cancer risk utilizing interpretive descriptive methods. In this study, four of the twenty two survivors interviewed had the history of breast cancer, which isn't a strong

representation of the population of interest (Wilkins and Woodgate, 2011). All the participants in this study acknowledged that life after cancer comes with the risk of cancer recurrence and that reoccurring thoughts of fear of recurrence plagued the survivors (Wilkins and Woodgate, 2011). Consistent with the findings of Wilkins and Woodgate (2011), Allen Savadatti and Levy (2009) and Sadler-Gerhardt et al. (2010) also found fear of recurrence to be prevalent and persistent in samples of breast cancer survivors.

### **Communication**

Communication was a theme that was prevalent in most of the studies addressing un-met needs in the literature review. Researchers explored communication using surveys, focus groups and secondary analysis (Cheung, Neville, Cameron, Cook, and Earle, 2009; Kantsiper et al., 2009; Mao et al., 2009; Royak-Schaler et al., 2008; Yeom & Heidrich, 2009).

Cheung et al. (2009) surveyed cancer survivors and physicians regarding cancer survivors' expectations of physician participation in four areas: primary cancer follow-up, screening for other cancers, general preventive health, and management of existing comorbidities. This was the only study addressing communication that did not exclusively use breast cancer survivors as participants (Cheung et al., 2009). The percentage of breast cancer survivors was 50% in this study (Cheung et al., 2009). Cancer survivors anticipated greater oncologist involvement than they received (Cheung et al., 2009). Cheung et al. (2009) reported that PCPs indicated they felt they have a greater role to survivorship care. PCPs and oncologists reported conflicting perceptions of the role they would take in primary cancer follow-up, cancer screening, and general



preventive health (Cheung et al., 2009). Yet both PCPs and oncologists indicated they had responsibility to carry out health initiatives for the cancer survivors (Cheung et al., 2009). Use of health care providers may not have captured the multidimensional role that communication affords in the process of breast cancer experience.

Yeom and Heidrich (2009) performed a secondary analysis of data collected from 61 breast cancer survivors 64 years and older, to explore barriers to symptom management and to investigate whether barriers influence quality of life. This was an appropriate use of secondary analysis as the original data set also explored symptom management among breast cancer survivors (Coughlan, Cronin, & Ryan, 2007; Walker, 2005). This study had a small minority subset, which is expected in most secondary analysis research (Coughlan, Cronin, & Ryan, 2007; Walker, 2005; Yeom & Heidrich, 2009). Three possible barriers to symptom management were hypothesized: 1) negative beliefs about managing symptoms; 2) perceived negative attitudes of healthcare providers; and 3) difficulties in communicating about symptoms (Yeom & Heidrich, 2009). This study found older breast cancer survivors, with negative beliefs about symptom management, perceived negative attitudes from their HCPs, and those who reported difficulties communicating about symptoms had a lower psychosocial quality of life (Yeom & Heidrich, 2009).

The most frequent barrier reported by the breast cancer survivors was difficulties in communicating about symptoms with healthcare providers, 53% ( $N=31$ ) (Yeom & Heidrich, 2009). Yeom & Heidrich (2009) reported that approximately 34% of breast cancer survivors are reluctant to report symptoms for fear of being labeled a problem patient and 30% are unsure of which healthcare provider to contact. Breast cancer

survivors also reported concerns that primary care providers and oncology providers fail to communicate with each other (Mao et al., 2009; Yeom & Heidrich, 2009).

Mao et al. (2009) conducted a cross-sectional survey of 300 breast cancer survivors to describe survivors' perceptions of PCPs survivorship care. Breast cancer survivors reported they received good general care, psychosocial support, and health promotion messages from their PCPs (Mao et al., 2009). On the other hand, breast cancer survivors felt that PCPs did not play a central role in their cancer related needs and that the PCPs acted as if they did not want to overstep their role by participating in cancer care (Kantsiper et al., 2009). Cancer survivors reported that only half felt that their primary care provider was knowledgeable about late effects of cancer therapies and only 41% were knowledgeable about treating symptoms related to cancer or cancer therapies (Mao et al., 2009). Additionally, Mao et al. (2009) noted that the participants in this study gained reassurance from oncology specialists and value routine laboratory testing and diagnostics more so than from information that they were given about statistics and treatment guidelines (Kantsiper et al., 2009).

Royak-Schaler et al. (2008) conducted focus group sessions with 39 African American breast cancer survivors to explore communication experiences from diagnosis through follow-up care. The mean age of the breast cancer survivors in this study was 55 years and 86% reported it had been more than one year since the completion of treatment (Royak-Schaler et al., 2008). In this study, 95% of the participants reported the wish to have a more collaborative role in making medical decisions (Royak-Schaler et al., 2008). The quality and quantity of information disclosed to the survivor was also an issue (Royak-Schaler et al., 2008). Some breast cancer survivors reported they were

overwhelmed with too much information while others felt they received too little information (Royak-Schaler et al., 2008).

There were information gaps evident in this study, thirty eight percent of the participants in this study were unaware of the stage of their breast cancer at the time of diagnosis and 50% of the breast cancer survivors who reported treatment side effects had discussed the symptoms with their healthcare provider (Royak-Schaler et al., 2008). The breast cancer survivors in this study identified healthcare providers and brochures as their main source of information (Royak-Schaler et al., 2008). The survivors favored the opinion of other breast cancer survivors to all other modes of information transfer (Royak-Schaler et al., 2008). Older breast cancer survivors did not favor computer based methods of education and sources of information (Royak-Schaler et al., 2008).

The breast cancer survivors in this study voiced concern for recurrence, survivorship care and planning (Royak-Schaler et al., 2008). Participants reported difficulty developing and managing survivorship plans (Royak-Schaler et al., 2008). Despite this, many of the survivors developed some type of survivorship plan without specific guidelines from healthcare providers (Royak-Schaler et al., 2008). Although HCPs recommended physical activity and weight control to reduce recurrence risk, only 10% of the breast cancer survivors in this study reported that their healthcare provider had addressed these recommendations (Royak-Schaler et al., 2008). This study explored communication between African American breast cancer survivors and healthcare providers, further exemplifying the need for healthcare providers to be informed and engaged in breast cancer survivorship care (Royak-Schaler et al., 2008).

### **Analysis and Themes in the Literature Review**

The literature reviewed indicated the phenomenon of breast cancer survivorship is present in women diagnosed with breast cancer, but there is a lack of theoretical framework evident in the fragmented presentation of the literature (Pelusi, 1997). Participant demographics varied with the majority of articles reporting the ethnicity of the participants as being Caucasian or the races and ethnicities of the sample were not reported. The majority of the studies presented findings that may not be generalized to minorities who are diagnosed with breast cancer.

Age range for the majority of the subjects varied between 26 to 87 years of age, with the mean age falling between 50-60 years in all of the studies. This is consistent with literature reporting that young women feel the breast cancer information available is not geared for their age groups (Dizon, 2009; Duffy and Allen, 2009; Gould, Grassau, Manthorne, Gray & Fitch, 2006; Gorman, Usita, Madlensky & Pierce, 2011). These findings will be used to incorporate a diverse sample in the proposed study.

The timeframes in which research was conducted also varied from immediately after diagnosis to greater than five years after diagnosis. This range may reflect a lack of understanding of the process of breast cancer survivorship and lack of theory of the process of breast cancer survivorship. All of the studies that explored communication had a single focus of time that may not express the role that communication plays in the dynamic process of breast cancer survivorship. Both qualitative and quantitative research methods revealed themes regarding un-met needs, as shown in Appendix A. To date there

have been no grounded theory studies which attempt to illuminate the process of breast cancer survivorship from the perspective of the survivors.

### **Research Questions**

- 1) How do women who have been diagnosed with breast cancer process challenges of transitioning into long term breast cancer survivorship once they complete acute and adjuvant care?
- 2) What are the challenges the women themselves identify?
- 3) When does transitional survivorship begin and end for women who have completed initial treatment for breast cancer?

### **Summary**

A considerable amount of literature exists on breast cancer, survivorship, and the mediators of survivorship, but few studies address the process and experience of transition into survivorship. Few studies were located that examined the transition from patient to long-term survivor after the acute and adjuvant treatment for breast cancer and captured a woman's perspective. The empirical literature revealed survivorship was not defined consistently in regards to time. Although survivorship was acknowledged as a phenomenon common to the completion of treatment, most of the research focused on physical sequelae, psychosocial sequelae, and treatment. A significant gap in the literature was revealed to show that the process of transition into extended survivorship has not been explored holistically or thoroughly.

The current state of the literature on breast cancer survivorship indicates that women transition and experience the role of extended survivor for the rest of their lives (Kaplan, 2008; Leigh, 1996; Mullan, 1985; Pelusi, 1997; Thomas-MacLean, 2004). What is not known is the processes they utilize to transition from patient to extended survivor. The research questions that were used in this study address this gap in the literature and speak to requests from the National Cancer Institute and Institute of Medicine reports for qualitative research to be focused on survivorship populations.

## **CHAPTER III.**

### **Methods**

#### **Rationale for Choosing Grounded Theory**

The increased detection and decreased mortality of breast cancer has caused an influx of extended breast cancer survivors in the healthcare arena. The phenomenon of breast cancer survivorship has been identified with qualitative methods, yet is lacking explanatory theory (Allen, Savadatti & Levy, 2009; Pelusi, 1997). Therefore, grounded theory was chosen to study the process of transition survivorship in women who have completed treatment for breast cancer. Grounded theory allows the researcher to explore a phenomenon and build theory from concepts going through processes and transitions (Artinian, Giske, & Cone, 2009; Charmaz, 2010; Creswell, 1998; Glaser and Strauss, 1967; Glaser, 1992, 1998, 2008, 2011; Heath & Cowley, 2004; Speziale & Carpenter, 2003).

To obtain a profound understanding of human behavior and the sources that influence behavior in this population, qualitative inquiry methods will be used (Creswell, 1998; Denzin & Lincoln, 2003). The basis of grounded theory is embedded in symbolic interactions, which assume an individual's actions and communications express meaning (Blumer, 1969; Benzies & Allen, 2001; Morse, 2008). The grounded theory approach will be used to explore the transition process of patient to extended survivorship from the perspective of a woman with breast cancer.

Qualitative description is useful when description of phenomena is desired (Sandelowski, 2000, 2010). This method differs from traditional qualitative research as the approach as it originated in nursing rather than social sciences. Qualitative description

uses inductive rather than deductive investigation of a clinical phenomenon for the purpose of capturing themes and patterns within subjective perceptions in order to generate an interpretive description to inform clinical understanding (Sandelowski, 2000, 2010; Thorne, Reimer Kirkham, and MacDonald-Emes, 1997; Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). In this study, true to an interpretive description a purposeful sample was chosen, open ended questions were used and the data was coded to reveal themes (Sandelowski, 2000, 2010).

Inductive methods are used by the researchers to discover and generate theory (Artinian, Giske, & Cone, 2009; Charmaz, 2010; Creswell, 1998; Glaser and Strauss, 1967; Glaser, 1992, 1998 2008, 2011; Heath & Cowley, 2004; Speziale & Carpenter, 2003). Glaser and Strauss (1967) initially developed grounded theory as a research approach in which theory and theoretical propositions are induced through real world observations within a social setting or a particular experience. Glaser and Strauss (1967) developed their qualitative method within the healthcare arena dealing with chronic illness, specifically death and dying patients.

Grounded theory is used to explore social psychological processes, and is therefore a good fit for this research study. An expanded understanding of the social psychological process of extended survivorship may provide a subjective insight of the individual's experience; assist in the design of nursing interventions, and impact policy. This study will assist nurses to support breast cancer survivors emotionally and potentially may allow nurses the opportunity to augment the quality of life during the health wellness continuum of the breast cancer survivors they care for.



### **Description of Settings**

The study took place at public libraries or locations chosen by the participants in Upstate New York. The public libraries were selected because they are in locations familiar to the participants, and had adequate private space to conduct the interviews that provided the data necessary to answer the research questions.

### **Sample Characteristics**

The sample for this study was a purposive sample drawn from breast cancer survivors in a suburban community in Central New York. The community is an economically depressed, non-agricultural area with approximately 234,000 inhabitants who are predominantly Caucasians (United States Census Bureau, 2012). Interviews were conducted until there was evidence of theoretical saturation (Glaser and Strauss, 1967; Glaser, 1992, 1998; Speziale & Carpenter, 2003).

### **Protection of Human Subjects**

#### **Inclusion and Exclusion Criteria**

The sample included women who have been diagnosed with breast cancer, and who had completed initial treatment for breast cancer. The inclusion criteria study also mandated that participants be over the age of 18 years, as this study was tailored to adult extended survivors of breast cancer. Participants were required to speak, read and understand English. Exclusion criteria stipulate participants must be free of any type of cognitive impairment. To ensure that they were not cognitively impaired, the participants were asked the current date and location and were asked to draw a clock face with the hands showing a time specified by the researcher (Bickley, 2008).

**Recruitment**

A purposeful sample was sought and participants were self-identified. A presentation was made at a local breast cancer survivorship group and flyers (Appendix B) were handed out during this session with the support group, posted in community centers, libraries, and public places like shopping centers, gyms, and pharmacies throughout the suburban areas of a Central New York community. The intention was to recruit a variety of extended survivors with diverse social, cultural, and economic backgrounds, in order to provide variation in the subject population. With this in mind, advertisements were placed in areas that reach numerous individuals from diverse backgrounds including: Caucasian, Asian, Latina and African- American women.

**Informed Consent**

Prior to commencement of the study, approval from the university's institutional review board was secured (Appendix C). Additionally approval from Faxton St. Luke's Healthcare was obtained in order to access the breast cancer survivor group (Appendix D). Interested participants phoned the researcher in response to the advertisement. After the researcher discussed and explained the study, including the informed consent process, the potential subject was asked if she was interested in participating in the study. If the potential subject indicated she wanted to participate, a time and place was agreed upon by both parties to meet to discuss the study. Informed consent documents were completed at this time. The collection of demographic data and the interview took place after informed consent was given verbally and in writing by the participant (Appendix E). Demographic data included the year of diagnosis, year that treatment was completed, stage of breast

cancer at diagnosis, and the treatment undergone (Appendix F). If the patient was unclear or could not recall specific breast cancer history and or treatment modalities, there was not a review of the past or current medical records as the focus of this study was the subjective perception of the trajectory of breast cancer survivorship.

Potential participants were told the purpose and objectives of the research. Risks and benefits were explained in length. Participants were queried and encouraged to voice any questions or concerns. The participants were also given the chance to clarify any questions or concerns through dialog with the researcher.

The participant was asked to read and sign a separate informed consent to audio-taping of the interview (Appendix G). It was made clear to the participant that they had the right to stop the interview at any time, and participation in the research could be terminated for any reason. At each interview, each participant was reminded she has the right to stop the interview at any time, for any physical or emotional reason.

### **Time Duration**

Each interview session lasted approximately one hour in length. The total duration for an individual subject was two months as the participant potentially was needed to be re-contacted after completion of data transcription with a follow up phone call to clarify information collected in the data.

### **Confidentiality**

The participants were identified solely by number documentation. Personal identifying information was not linked during transcription and the interview process. The participants were informed of this process and the anonymity of participants was

protected. Additionally the participants were informed that comments made may be reported in the final study, but would be presented in a manner to protect anonymity. Files that contained participant identifying information and personal contact information were stored in a separate locked file discrete and distinct from the area in which the research data is stored.

All audio recording will be destroyed by shredding three years after the completion of the research. Research files and information are kept in a double locked area, accessible only to the primary researcher until three years after the completion of the study. At this time the written and audio data will be shredded.

### **Risks**

The potential for psychological distress was discussed with participants. Risks of elicitation of emotions based on past experiences were carefully described to participants prior to commencement of the interview and in the consent form. Stand-by psychological counseling was arranged for with Dr. Joanne Joseph, a psychologist who has had extensive expertise working with this population.

### **Benefits**

The benefits of participation in research interviews were highlighted in the consent. The agenda of the interviewer was not to fix problems, but to better understand the individual's perspective. Due to the nature of the research interview, there was a rotating triadic relationship with the interviewer in which the participant became the expert of their own phenomenological perspective (Gale, 1992). This allowed for unanticipated benefits of participation.

Benefits of research interview participation were reported, as the discussion of the social experience and disease establish a venue in which a voice is provided to the extended survivor to generate purpose, catharsis, affirmation, empowerment, and emotional healing (Hutchinson, Wilson, & Wilson, 1994; Murray, 2003). Patients' dialog about concerns may have assisted them, as talking about concerns may help women deal with the issues that accompany breast cancer survivorship (Hutchinson et al., 1994; Murray, 2003). Additionally the participants in this study were given a \$20.00 gift card to a local grocery store as compensation. The honorarium was granted even if the participant withdrew from the study.

### **Data Source and Collection**

Data for the study was collected by completing: 1) a demographic data form; 2) in-depth research interviews; 3) observational notes; and 4) field notes. The demographic data form (Appendix F) was used to collect data on: age, sex, ethnicity, marital status, educational background, employment/disability status, type of breast cancer, what treatment the participant received, and years since completion of treatment. The demographic information was collected to determine group characteristics. The information collected for demographic, diagnosis and treatment was self-reported by the participant.

The interview style consisted of both broad and focused questions. Broad open-ended questions were used to stimulate discussion of thoughts and feelings about extended survivorship. Focused questions and prompts were used to elicit more specific information from participants about their actions to attain and maintain psychosocial health after the completion of breast cancer treatment. The focus questions also elicited

information about processes used to modify and maneuver through adversities after completion of treatment.

The researcher also used prompts congruent with the objectives of the study to clarify and expand responses if necessary. Additional focused prompts were designed as themes emerged in the interviews. The research interview guide evolved and developed during the course of the data collection as guided by the developing theory (Appendix H). Interview questions varied after the initial interview, as questions were incorporated into interviews as additional information emerged. The initial interview guide was designed to evoke meanings of extended survivorship from the perspective of the extended breast cancer survivor. The interview guide also focused on the processes used to modify and maneuver through adversities after completion of treatment (Appendix H).

Each participant was asked to describe situations when she knew something had changed in her health and psychosocial status after the completion of treatment for breast cancer. Participants were asked to answer the questions until they felt they had no further information to add to the topic. The research interviews were audio-taped and transcribed verbatim by the researcher.

Observational and field-notes were taken during and after each recorded interview. Examples of non-verbal communication, physical symptoms, emotional expression, body mechanics, and dress were recorded in the field-notes. These notations were incorporated during transcription of the interviews to provide a multifaceted lens of the interview scene and context of the interaction. The interview process continued until the categories reached saturation.

### **Data Analysis**

Glaser and Strauss (1967) stated that the process of grounded theory is an interpretive process in which interviews are used to interpret and find meaning of concepts derived through the data. Grounded theory concentrates on how individuals interact in relation to the phenomenon under study (Dey, 1999; Creswell, 1998). Key components of Glaserian grounded theory are: preparation, data collection, analysis, memoing, and sorting to create a theoretical outline (Christiansen, 2009).

Data analysis for the study took a Glaserian approach in which data collection, analysis and memoing was ongoing and concurrent throughout the timeframe of the study (1978, 1998). Glaserian Grounded Theory (1978) approach uses constant comparative methodology including: coding, memo writing, and sorting. Constant comparative methodology employs collection of data with concurrent analysis. Analysis of the data took place as soon as possible after transcription was completed.

Upon data analysis, a core variable was found which served as the foundation of theory generation. Core variables often recur frequently, link data, allow for variation from various population backgrounds, become more detailed, and have implications for formal theory (Glaser and Strauss, 1967; Glaser, 1992, 1998). The generation of categories and properties of the phenomenon being investigated drove the subsequent interviews until the data was saturated. This allowed the interview guide and probes to expand and become tailored to the phenomenon.

### **Description of Coding Procedures-Substantive Coding**

Glaser (1978, 1998) identifies open coding and selective coding as substantive coding. Both methods of coding allow for the researcher to discover codes that lay within the data (Glaser, 1978). Initially, open coding will be used in the proposed study.

#### **Open Coding**

Consistent with Glaserian grounded theory analysis; the data was coded at three levels. Each interview was digitally taped and transcribed. The interviews were transcribed leaving wide margins to the right in order to write notes and codes. Atlas ti software was used as a depository to code, store and memo during analysis. During the first level of analysis, the data was examined with line by line coding (Glaser and Strauss, 1967; Glaser, 1992, 1998; Speziale & Carpenter, 2003).

Three questions were used to guide coding (Glaser and Strauss, 1967; Glaser, 1992, 1998; Speziale & Carpenter, 2003):

1. What is going on?
2. What is the situation?
3. How is the individual or group managing the situation?

Data was coded line by line to fracture the data into nouns formed from a verb or gerund tense. Words ending with “ing” were used to code actions recognized within the data. This was done to enable the data to be raised into a conceptual level at a later time. Open coding is used in grounded theory to see which direction the study will follow (Glaser, 1978). Codes reflected what the participant said and also what the researcher observed.



The interviews were re-coded on three different occasions. After the initial interview was coded, the second interview was coded in a similar fashion and the data was examined for common constructs that were clustered. Further interviews were open coded and compared with ideas and relationships described in the researcher's memos. As the categories unfolded, some categories were re-coded or combined with other categories. "Open coding both verifies and saturates individual codes," (Glaser, 1978, p.60) while memos "are theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding" (p.83). Open coding was maintained until all codes were fully investigated and developed. Upon the conclusion of the last interview, all codes were sorted to certify fit. Glaser (1978) cites that at this point of data analysis "In short a total saturation occurs: all data fit" (p.60).

### **Selective Coding**

Selective coding begins when the researcher "can see the prospects for a theory that...copes with the data entoto" (Glaser, 1978, p.61). Once a core variable or category was identified, following Glaser's recommendation, the coding then became selective. "The analyst delimits his coding to only those variables that relate to the core variable in sufficiently significant ways to be used in a parsimonious theory" (Glaser, 1978, p.94). The researcher continued the interviews and coding until saturation of the core variable was achieved.

### **Theoretical Coding**

Upon saturation, theoretical coding was used to further analyze the data. "Theoretical codes conceptualize how the substantive codes may relate to each other as hypotheses to be integrated into a theory" (Glaser, 1978, p.72). Theoretical codes

examine and hypothesize the relationships between substantive codes to be integrated into the theory (Christiansen, 2009). Glaser (1978, 1998) identifies 26 coding families that are helpful to the researcher when theoretical coding takes place. Examination of these codes may be helpful if they fit the data. A further exploration of the literature of substantive codes that were significant was conducted per diem.

### **Memoing and Theoretical Sorting**

Theoretical memoing is considered by Glaser (1978) to be “key to formulating theory” (p.116) and is “the core stage in the process of generating theory, the bedrock of theory generation, its true product is the writing of theoretical memos” (p. 83). If the researcher does not apply and use theoretical memoing, he or she is not engaged in grounded theory. Although data collection, analysis, and memoing are concurrent, memoing should take precedence. Memoing is documentation of what is emerging from the data and analysis in real time. Memos capture ideas, and ideas are fragile and forgettable. Glaser (1978, 1998) recommends that memos should be written down immediately in order to capture the moment or thought. Extensive memo taking was used in the study via manual notes and also as freehand drawn visuals created by the researcher to capture the researcher’s mind set (Appendix I).

Theoretical sorting refers not to data organization, but to conceptual sorting of memos into an outline of the emergent theory, which allows the relationships among concepts to be seen. Theoretical sorting often instigates additional memos and potentially additional data collection. This process allows for dense, rich conceptualization grounded in the data and not solely descriptions of data (Glaser, 1978, 1992, 1998, 2001).

## **Rigor**

### **Trustworthiness**

Rigor is essential to research documentation, procedure, and research ethics (Rolfe, 2006). Although discussed with intense passion over the past 30 years, there are currently no standard accepted criteria for rigor in qualitative research (Rolfe, 2006; Sandelowski & Barroso, 2002). In qualitative research, the term trustworthiness is used rather than validity to describe the processes employed to assure rigor of the study.

Sandelowski (1993) posits that validity is geared toward a quantitative, positivist view, and qualitative studies should employ “trustworthiness” rather than validity. Trustworthiness becomes a “matter of persuasion whereby the scientist is viewed as having made those practices visible and, therefore, auditable” (p. 2). Trustworthiness involves establishing credibility, transferability, dependability and confirmability (Lincoln and Guba, 1985; Denzin & Lincoln, 2011).

Credibility, transferability, dependability, and conformability all are themes laced into the recommendations of the credible authorities mentioned above. Glaser (2001, 2008, 2011) adds external validity as an additional recommendation. For the purpose of this paper, a conglomerate of trustworthiness criteria grounded from the recommendations of Glaser (2001) was employed.

## **Credibility**

Credibility is the confidence in the truth of the findings (Creswell, 1998, Glaser 1978, 1992, 1998, 2001; Lincoln and Guba, 1985). Credibility is established by using techniques to establish credibility such as: prolonged engagement, persistent observation, triangulation, peer debriefing, negative case analysis, referential adequacy, and member

checking (Creswell, 1998; Lincoln and Guba, 1985). Prolonged engagement, peer debriefing, and member checking was used in this study.

### **Prolonged Engagement**

Prolonged engagement is defined as “investment of sufficient time to achieve certain purposes...and building trust” (Lincoln and Guba, 1985, p. 301). This technique was used extensively with exhaustive interviews to develop rapport and participant trust.

### **Peer Debriefing**

Peer debriefing “is a process of exposing oneself to a disinterested peer in a manner paralleling an analytical sessions and for the purpose of exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer's mind” (Lincoln & Guba, 1985, p. 308). Peer debriefing occurred throughout this study, formally and informally with: the dissertation committee, dissertation chair, colleague faculty, and colleague doctoral students.

### **Member Checking**

Member checking took place when data, analytic categories, interpretations, and conclusions were discussed and tested with study participants. Member checking was used throughout this study as themes and theory emerges. Denzin and Lincoln (2007, 2011) posit that member checking is a crucial technique for establishing credibility. However, this technique is controversial. Sandelowski (1993) rejects member checking as she feels this practice threatens validity and credibility. However, in grounded theory, it is recommended that member checking take place throughout the interview process

(Creswell, 1998, Denzin and Lincoln, 2007, 2011; Glaser 1978, 1992, 1998, 2001, 2008, 2011; Lincoln and Guba, 1985). Additionally, to further authenticate the participants interviews, all the interviews were transcribed by the author and proof-reading was done while listening to the recorded session.

### **Transferability**

Transferability pertains to the research external reliability. The aim of a well-designed and executed grounded theory study is to gain greater in-depth understanding of a process with a set of results that may generalize or apply to a great degree outside the specific boundaries of that original study's circumstances or transferability.

Transferability refers to the extent to which the results of a qualitative research study can be generalized or transferred to other populations, contexts, or settings (Denzin and Lincoln, 2007,2011).

### **Thick Description**

Trustworthiness of qualitative studies is established with a documented audit of actions and developments of the researcher; this process is also referred to as thick description (Koch, 2006; Ryan, Coughlan, & Cronin, 2007; Sandelowski, 1993). Thick description was first defined by Ryle (1949), then later used by Lincoln and Guba (1985) and Creswell(1998). The researcher describes field experiences by identifying patterns of cultural and social relationships, in context of the research study (Holloway, 1997).

Thick descriptions are elaborately detailed descriptive data that provide the reader with sufficient information to judge the themes, labels, categories, or constructs of a study in order for the reader to critique the appropriateness of applying the findings to

other populations. From a qualitative perspective transferability is primarily the responsibility of the reader, not the researcher of the study. However, the researcher has the responsibility to provide clear, concise, thick descriptions of the research process and decisions. Strategies used to achieve transferability include thick descriptions and purposive sampling (Creswell, 1998; Lincoln and Guba, 1985).

### **Dependability**

Dependability pertains to reliability, and is another criterion used to judge the trustworthiness of a qualitative research process (Koch, 1994, 2006). This is achieved through the researcher's audit trail and inquiry audits from a neutral researcher. An audit trail allows the reader to follow the evaluations, assessments, and decisions made in the chronological order of the study. Dependability also emphasizes the need for the researcher to account for the serendipitous, varying context within which research occurs. Sandelowski (1986) clearly addresses dependability as the term fittingness in her statement, “a study meets the criterion of fittingness when its findings can 'fit' into contexts outside the study situation and when its audience views its findings as meaningful and applicable in terms of their own experiences”.

### **Inquiry Audits**

External audits involve having a researcher not involved in the research process examine both the process and product of the research study. Inquiry audits in the form of external audits and confirmability audits bolster trustworthiness by addressing dependability and confirmability. The purposes of external audits are to evaluate the

accuracy and evaluate whether or not the findings, interpretations, and conclusions are supported by the data.

### **Confirmability**

Confirmability is the degree of neutrality or the extent to which the findings of a study are shaped by the respondents and are free of researcher bias, motivation, or interest (Lincoln and Guba, 1985). The researcher who conducted this study had scant exposure to extended breast cancer survivors in her personal and professional realm.

Confirmability requires that the researcher demonstrate how the method interpretations have been attained. Guba and Lincoln (1989) state confirmability is established when credibility, transferability, and dependability are achieved. Techniques to establish confirmability include: confirmatory audit, audit trail, triangulation, and reflexivity (Denzin & Lincoln, 2011; Lincoln & Guba, 1985). The confirmatory audit and audit trail was used in this study as discussed in the following section.

### **Description of Audit Trail**

An audit or decision trail is a holistic, documented description of the research steps taken from the commencement of a research project through the elaboration and reporting of the research findings. In order to have a clear description of the research direction, it is imperative to maintain confirmability. The audit trail for this study included research design, data collection choices, and conclusions.

In concert with Denzin and Lincoln's (2003, 2011) recommendations, the following groups of data was included in an audit trail: 1) raw data; 2) data reduction and

analysis notes; data reconstruction and synthesis products; 3) process notes; 4) materials related to intentions and dispositions; and 5) preliminary development information. The data and data collection procedure was well documented within the verbatim transcriptions of the interviews that were conducted. The evidence for decisions were clearly documented and presented. Review and approval by the dissertation committee also aided in ensuring comprehensiveness of the audit trail. A final report including connections to existing literatures and an integration of concepts, relationships, and interpretations was implemented in the form of this dissertation. The evidence for conclusions were presented and theoretical statements will be linked to the data (Burns, 1989).

### **Reflexive Journal**

Reflexivity is "...a critical gaze turned toward the self and the making of a research product" (Koch & Harrington, 1998, p. 888). The use of a reflective research journal fosters reflexivity and a reflexive research design. This type of journal will be kept during this study. The researcher addressed the confirmability through operationalizing reflexivity by making regular journal entries during the research process and through dialog with the dissertation chair. In this journal, the researcher recorded methodological decisions and the rationale for the decisions, the planning and management of the study, and reflection upon the researcher's own principles, feelings and interests.



### **Summary**

This chapter describes the rationale and methods to be employed in this study. The researcher's procedure for obtaining participants, recruitment, inclusion criteria and trustworthiness were discussed. Precautions and safeguards to protect this vulnerable population were outlined to ensure appropriate institutional review board approval. Data sources and Glaserian grounded theory methods of data collection and analysis were used in the study. Rigor was used to maintain trustworthiness and complete audits.

## **CHAPTER IV.**

### **Historical and Sociocultural Context of the Research**

Data from informants obtained through purposeful sampling is imperative to the grounded theory research method. The focus of this study was to explore the process women endure after they have completed treatment for breast cancer, thus the criteria of breast cancer was the similar role that influenced the personal history and social realms of the women in this study. This chapter presents the individuals who participated in this study through summaries of the informant group's demographic and past breast cancer treatment history. This chapter also outlines the audit trail of purposive sampling used in this study.

### **Introduction to the Participants**

The sample was made up of 12 participants recruited over a four month period. The age range of the participants was thirty-nine to eighty-one. The mean age was 58 years ( $SD=13.37$ ). The sample was exclusive to females (100%). All of the participants had been diagnosed with breast cancer and had completed initial treatment at the time of interview. All of the individuals could read and speak fluent English. All completed a demographic sheet (Appendix F). Subject characteristics are summarized in chart format in Appendix M. Additionally, narrative Summaries can be found in Appendix K.

### **Demographic Data**

The ethnic origin of the participants was Caucasian (100%,  $N=12$ ). Fifty percent ( $N=6$ ) of the participants were currently married, seventeen percent ( $N=2$ ) were divorced,

eight percent (N=1) were partnered, seventeen percent (N=2) were single, and eight percent (N=1) were widowed. One of the participants was widowed then remarried. Ten of the participants had children (83%) and two participants did not have any children (17%).

Education background ranged from high school equivalency to graduate degrees. High school diplomas or equivalent were obtained by thirty-three percent (N=4) of the participants. The majority, sixty-seven percent (N=8) of the participants had completed three or more years of college and fifty-eight percent (N=7) graduated with either bachelors or graduate degrees from college. Graduate school had been completed by seventeen percent (N=2) of the participants. Employment status of the participants varied. Four participants were employed full-time (33%), one participant was employed on a part-time status (8%), five participants were retired (42%) and two participants were disabled (17%).

The time range since completion of treatment for breast cancer varied from three months to twenty six years at the time of the interviews. All of the participants had breast cancer (100%), two participants had experienced recurrence (17%), one was in the midst of being worked up for metastatic cancer (8%) and one had confirmed metastatic bone cancer (8%). The treatment that the participants had undergone varied. The majority, sixty-eight percent, of the participants underwent chemotherapy, radiation and mastectomy to treat their breast cancer. Two of the participants (17%) had only a mastectomy for treatment for breast cancer. Three participants (25%) had a lumpectomy, one of whom had a mastectomy following her lumpectomy. Ten participants had

mastectomies (83%), seven having had a single mastectomy (58%) and three having had double mastectomies (25%).

Ten of the participants (83%) had resumed primary care after treatment for breast cancer. One participant (8%) only saw a primary care provider for sick call issue and one participant (8%) had not gone back to primary care despite being out of treatment for breast cancer for eight years. Nine of the participants (75%) continued to see the oncology team and three had been discharged from oncology care (25%).

### **Purposive Sampling**

The objective of qualitative research is to collect descriptive understanding of human behavior and the purpose and motivation for that behavior (Denzin & Lincoln, 2010). The qualitative method of grounded theory is used to explore processes that occur within certain populations. Grounded theory focuses on processes present in certain populations of interest and purposive sampling is employed with this method (Glaser, 1998). Purposive sampling strives for access to a population that has experienced a common phenomenon in order to explore the unique characteristics of that population of interest. The goal of purposive sampling is to acquire data that represents similar incidents or events (Sandelowski, 2000, 2010). For this study, sampling was purposive and continued until the sample encompassed a variety of participants with different treatments, ages and time since treatment was completed.

### **Purposive Sampling Established From Response to Flyer**

Many potential participants responded to flyers that were posted on bulletin boards in community meeting places and markets. The first two participants and

participants four and seven contacted the researcher in response to flyer posted on a community bulletin board at a market. Participant One was selected because she recently finished treatment for breast cancer three months prior to participating in the study. This participant was enthusiastic and willing to verbalize her recent experience. Participant Two was selected as she had been done with treatment for thirteen years. The third and sixth participants contacted the researcher in response to hearing about the study from word of mouth. Participant three was sampled as she had finished treatment thirteen years ago and was very active in the breast cancer community in an adjacent township.

Participant four was sampled as she was vocal and willing to share her experience, she had been done with treatment for five years. The fifth participant contacted the researcher in response to hearing about the study from her neighbor, a family nurse practitioner. This participant was sampled as she voiced many struggles after leaving treatment with body issue concerns. Participant six was sampled as she had completed graduate school while in treatment.

### **Purposive Sampling Established on Response to Presentation of Research**

Additionally the researcher presented her research at a local healthcare facility interdisciplinary institutional review board meeting and to a local breast cancer support group. This method of advertisement via live presentation to the population of interest was extremely successful as multiple potential participants contacted the researcher directly. Participants seven, eight, nine, ten and twelve contacted the researcher after the presentation.

**Purposive Sampling Based on Theoretical Sampling**

Theoretical sampling is purposive sampling guided by the evolving theory in attempts to select participants that will most likely provide the concepts and categories of the developing theory (Glaser, 1998). Once a preliminary theme had emerged from the data, attempts were made to theoretically sample participants. All of the remaining participants had unique struggles, varied survivorship timeframes and had varied outcomes including reproductive health, breast feeding, metastasis and recurrence. Sampling decisions were contemporaneous based on constant comparison of the data. Sampling continued until all of the concepts were fully expounded and no new information was revealed.

Participant seven was selected as she was breastfeeding when she found her mass and had two additional babies while in and after treatment. Her situation was unique and represented the aspect of family roles. Participant eight was sampled as she had been out of treatment for twenty-four years and had experienced recurrence. The researcher chose her as recurrence is a reality that many breast cancer survivors endure. Participant nine was sampled as she was in the midst of testing for metastatic breast cancer; this participant was chosen as she was in the midst of a cutting point crisis.

Participant ten was sampled as she was active in the breast cancer community and had been done with treatment for twenty-six years. She was sampled to further explore long term breast cancer survival. Participant eleven was a snowball outcome as she was told about the research study by participant nine. This participant was sampled as she had metastatic breast cancer which can be an outcome of breast cancer.

At this point the researcher felt that the data was saturated as the collected data became superfluous and redundant. The researcher attended a Grounded Theory Institute Conference and met with Barney Glaser to discuss the technique and findings. Dr. Glaser encouraged the researcher to write up the theory that had emerged and confirmed saturation. The researcher had arranged for interview twelve prior to the conference. Participant twelve was chosen to sample as she had been done with treatment for five years and had faced recurrence. During this interview the participant described all aspects of the hypothesized theory. After discussing her story, the researcher shared the hypothesized theory. At this point the researcher concluded the data was theoretically saturated.

### **Summary**

In this chapter, the participants of this study were introduced. Sampling methods used in this study were presented. Purposive sampling methods by flyers, presentations to the population of interest and theoretical sampling methods used in this study were exhibited.

## ***CHAPTER V.***

### **Description and Discussion of the Themes**

Grounded theory explores the main concerns of the population of interest and investigates the process or patterns that this population uses in response to a concern (Artinian, Giske, & Cone, 2009; Charmaz, 2010; Creswell, 1998; Glaser and Strauss, 1967; Glaser, 1992, 1998, 2008, 2011; Heath & Cowley, 2004; Speziale & Carpenter, 2003). This method inductively generates theory from descriptions from the participants themselves. It is the purpose of grounded theory research to uncover the latent processes that are occurring in response to the central concern of the population of interest (Glaser, 1992, 1998, 2008, 2011). This allows theory to emerge unforced from the data.

Discovering the main concern of the participants is a central property of classic grounded theory methodology (Glaser, 1992, 1998, 2008, 2011). Although classic Glaserian method discourages the use of interview guides, interview guides are often used to begin the research with a problem question in mind to frame the study. Although this variation of the method is less open, it does allow the scope of the study to be defined and guide the researcher. Additionally, the main concerns of the participants are discovered over the course of data analysis and the research question may or not be answered.

The researcher in this study chose to use the following research questions: 1) How do women who have been diagnosed with breast cancer process challenges of transitioning into long term breast cancer survivorship once they complete acute and adjuvant care? 2) What are the challenges the women themselves identify? 3) When does



transitional survivorship begin and end for women who have completed initial treatment for breast cancer?

### **Core Categories and Basic Social Processes**

Core categories are main themes that represent the processes that the participants use to resolve their main concern (Glaser, 1998). Core categories had the following criteria: 1. Must be central and relate to the most other properties and categories, 2. Reoccurs frequently in the data, 3. Takes greater time to saturate due to the fact is related to many other categories, 4. Relates easily and has meaningful connections to other categories, 5. Has “clear and grabbing implications for formal theory”, 6. Has “carry-through” or doesn’t lead to dead ends in the theory, 7. Has variability, 8. While accounting for variation also is part of the problem, and 9. Can be any type of theoretical code: process, condition, two dimensions or consequence (Glaser, 1978, p. 95-97).

All basic social processes are core variables, but not all core variables are basic social processes (Glaser, 1978). In addition to the above discussed criteria, in order for a core variable to be classified as a basic social process in addition to the above discussed criteria, the core variable also must comprise two or more emergent stages that “differentiate and account for variations in the problematic pattern of behavior” and be temporally variable (Glaser, 1978, p.97). The basic social process describing how women with breast cancer survive psychologically was Negotiating Emotional Order. The stages of this process were: (a) losing life order; (b) assisted life order; (c) autonomous life order; (d) accepting cannot control cancer; and (e) creating emotional order.

In this study, the basic social process describing how women with breast cancer perceive their illness and take action was negotiating. Participants were attempting to bring the psychological aspect of having breast cancer into a state of order by negotiating control with cancer, themselves and external factors. Decisions made with regard to the women's psychological situation and time points in the treatment/survivor trajectory involved attempting to regulate feelings of uncertainty and fear due to cancer. Negotiating emotional order is the overarching core category which emerged from the data; it explains how participants managed their main concern of fear of cancer and facing their mortality. One participant discussed a time of emotional duress during the breast cancer trajectory describing loss of control in this reflective quote: "I had no control over anything. I think it came from not having any control over the disease but I felt like I lost control over my entire life". This statement reveals the main concern of the breast cancer survivors, negotiating emotional order to maintain quality of life.

Initially this category was labeled as Control, with sub properties of losing control of body/health due to breast cancer, taking control of care decisions, letting guardian take control of care, taking control of emotions, social support taking control, social support giving control and compartmentalizing emotions to regain control. Initially, the potential core category was given the "best fit" conceptual label as recommended by Glaser (1978, p.94). Evidence of a potential core category emerged through coding data in subsequent interviews.

With constant comparison, control was also evident in the initial interviews. Confirmation of the core category occurred through analyzing data from the seventh, eighth and ninth interviews. As theoretical sampling occurred with constant comparison

of the incidents in the interviews, the core category morphed to Negotiating Emotional Order, which offered the best conceptualization of the latent process inherent in the variables and their properties. With further reflection on the data, best fit was redefined as it was evident that the attempt to control was a means to create emotional order, as the participants described the cutting point of accepting there is no way to control cancer.

One participant stated:

Just my philosophy on life. I don't know. It's weird. Some things you can't control ...if you can't control it has to be happening for some reason. You got to go with it and deal with it and make the best of it that you can. Other things in your life you can control, it's not like it's happening when you control it the way you want.

Negotiating Emotional Order took into account the variables of control but also described the patterns that the participants described that they went through when there was a concern that they could not control, for example, recurrence of cancer and their mortality. When the data was fractured and theoretically sampled order rather than control described the basic social process. It was evident that the participants struggled with the aspect that they could not control cancer but in response to this, attempted to gain personal emotional order. Negotiating Emotional Order accounted for the pattern variation in the behavior that was analyzed from the data.

### **The Theory of Negotiating Emotional Order**

#### **Temporal Aspects of the Theory**

Although all of the narratives were different from each other, throughout the study the actions and decisions expressed by the participants illuminated the perpetual struggle to maintain emotional order and live their lives. For some, order meant

compartmentalizing negative thoughts and emotions that they could not control. For others, they accepted the fact that they could not control cancer but projected order onto other aspects of their lives. For the participants, the struggle for emotional order was present from the time period when the survivor found the abnormality into long-term survivorship. The perpetual struggle with emotional order after the diagnosis to the end of the survivor's life was evident in the data. For participants who had endured recurrence the stages also became cyclic. One participant emphasized the continual quality of the main concern voiced by the participants as she described her experience: "It's been 13 years. It's gone but it's not".

### **Cutting Points**

Although the focus of the study was on the process of survivorship after ending adjuvant treatment, all of the participants referenced emotions which began at the time of finding the breast mass and at diagnosis. The researcher was careful to allow serendipitous conversations about all aspects of the survivorship trajectory and this allowed for a holistic lens when exploring the emotional process that was occurring. Glaser (1978, p. 76) emphasized the importance of cutting point families, "Cutting points are very important in theory generation, since they indicate where the difference occurs which has differential effects". Glaser (1978, p.76) defines cutting point families as "boundaries, critical junctures and turning points" that emerge from the data.

The theory of negotiating emotional order involves six cutting points that the breast cancer survivors felt were significant and emotionally disorderly time frames. Cutting points that indicated emotional disruption included: 1) Finding an Abnormality,

2) Waiting for Conformation of Diagnosis, 3) Confirmation of diagnosis, 4) In Treatment, 5) Completing Treatment, 6) Moving On-Accepting What Can Control. These cutting points were heavily grounded in the data and thought to be significant. See Addendum K for the output of the codes that were grounded in the data.

### **Emotional Modifiers**

Forces that modify negotiating emotional order throughout all of the stages included: spirituality, humor/positive outlook, information and interpersonal influences. All of these factors influence the breast cancer survivor from diagnosis to long-term survivorship. Several of the modifiers were found to have paradoxical properties. Each one is dynamic and will be discussed.

**Spirituality.** Spirituality added in modifying the breast cancer survivor attempting to negotiate emotional order. Several of the participants used spirituality as a buffer to negotiate negative feelings, to make sense out of the diagnosis and gain acceptance of the experience they went through. Several drew from their faith in hard times and also with accepting they do not have control over cancer. One participant had been diagnosed with bone metastasis and stated she did not have any fear about her disease because of her faith. When asked how she handled her emotions she answered: “God. You just sit there, you pray and you go through all this, plus I’ve got a lot of people praying for me”. Another participant also discussed spirituality at length:

It gave me a lot of faith. A lot of faith. Faith in people. I have always had a certain amount of faith in God. Not when I got sick. When I got sick my husband was also tested for, he had to go through prostate evaluation because his PSA was high. So he had to go through biopsies and he came home and he said M. if they diagnose me with cancer right now I will know there is not a God. He was losing his faith in God because there is no way that God would put me through this and

you through this at the same time. He said I would lose all the faith. I was like oh D. because he was born and raised Catholic. I was like you know you just can't throw your faith away because of things that happen to us along the way. Thank God it came back it was only inflammation. He runs every day, he rides his bike every day it was all the things it could have been. But they scare the heck out him anyway. I think sometimes there is no way he could have handled something like that at that time. There is no way. And I tell him God won't give you more than you can handle and you handled me just fine. It does test your faith. It does but you have to believe in something bigger and better. You have to or all of this isn't worth anything.

**Humor and Positive Outlook.** Several of the breast cancer survivors used humor to modify the negative emotions of the disease trajectory. Using humor rather than focusing on negative feelings was evident as one participant stated she knew she could move on once she could joke about cancer: "I knew I could move one. Just not worry about it. And today I can joke about it. I have a new breast and an old breast. One stays up the other goes down". Another participant further expanded on humor:

My sense of humor has always been my best friend, and I think I probably used my sense of humor a lot. I remember when I went back to work one of the fellows at work, I hadn't seen him in a while, and he always called me K. He said K., where the heck have you been? I haven't seen you in a long time. I said I had to have some surgery. Geez, I hope it wasn't anything serious. He obviously hadn't heard. I said, well, I had to have a mastectomy. He said: you did. I thought you had those off years ago. I started laughing so hard, and I just thought, it felt so good to laugh so hard, and I thought okay, that's the medicine. That's the medicine, the laughter. I just let my sense of humor be my guide.

The ability to use humor seemed to act as a buffer and in this sample was evolutionary. The participants noted as time passed they felt like they were doing well emotionally if they could employ humor to their situation

**Information.** Information was gained in many different ways in this sample via the Internet, media, seminars, formal support groups, informal information sharing by other breast cancer survivors. Information was a powerful moderator, as information is

easily accessible through the Internet and in the popular media. One of the participants also warned of incorrect or harmful information: “I try to be very careful, I try to research it. Through writing my book I’ve learned the top 5 websites to go to research things that have good information rather than just following the Internet”. Participants in this sample attempted to create emotional order throughout the breast cancer trajectory by seeking information and self-education. The breast cancer survivors used information to self-educate themselves about the disease, treatment modalities, and cancer resources in their community. Additionally the survivors sought information through seminars, published books and through support groups.

Even though treatment ended, many of the breast cancer survivors continued to research breast cancer for treatments that might benefit them. They sought such information to advise other breast cancer survivors. Two of the participants had started breast cancer support groups, and then became facilitators for their community breast cancer support groups. Another participant had written a book to aid other breast cancer survivors through their disease trajectory. It seemed important for the participants not only to gain information, but also to pass the knowledge on to others. One participant discussed why she thought women went to support groups to gain information about breast cancer:

They want to know what is happening all the time with breast cancer because once you've had breast cancer, somebody's going to knock on your door or call you up and say, my co-worker was diagnosed, my sister was just diagnosed. What should I do? Where should I go? The women that are in the group really want to be educated and know about everything so that they can answer those questions.

This sample also gained information from other breast cancer survivors, both formally and informally. Subject Eight spoke about attending support groups as way to

learn more about breast cancer from other breast cancer survivors and assess her personal status:

It was very helpful because there were so many women there that told their stories. Actually, I felt good because my tumor was discovered so early that in comparison to many of the others, I felt that I had a better prognosis. I learned more about what sort of other types of breast cancer there could be and what they were doing, and of course, it was just at the beginning of, they said, the lumpectomies. Chemotherapy for breast cancer was reasonably new, so there were still experimenting with a lot of different drugs. Tamoxifen was brand new. They were just beginning to use that. There was a lot going on in the field. I found it very informative, and I think it certainly helped me realize that basically I was in a good position.

In some cases the breast cancer survivors were misinformed by non-credible authority web pages. In other situations, information caused fear for the breast cancer survivors. In the case of one participant, she stated she was frightened by information she received at a seminar thus displaying the paradoxical property of this modifier:

I went to the Carol Baldwin; she had a thing down there. A matter a fact I have a picture with her. There was another one I didn't know what to do. I went to see, she had a what do you call it? At the Radisson where they got all the cancer people, awareness. It was a dinner then she talked and everything about her experience. It kind of scared me more in a way.

**Interpersonal Influences.** Interpersonal influences were the most common code to emerge from the data analysis. (See Addendum K). Interpersonal influences included interactions with family, relationship partners, friends, acquaintances, health care providers, and other breast cancer survivors. Interpersonal factors were present and contributing factors as the breast cancer survivors negotiated emotional order. Key to interpersonal influences was the interaction of communication as well as meaningful actions. Interpersonal influences had a paradoxical dimension, as they can give support or take away support to the breast cancer survivor.



Interactions were reported as actions and communication. Interpersonal influences, information and prior experience were found to paradoxically influence emotional order both positively and negatively. For example, the role of healthcare providers as an interpersonal influence was very evident in the data throughout all of the cutting points. The participants frequently discussed how the healthcare provider aided or caused emotional duress. A participant shared her displeasure on being told she had breast cancer by a surgeon via a phone call while she was at work an hour from her home:

On Tuesday I get a phone call from my surgeon. He was on vacation, he called me while I was at work. He told me it was a malignant tumor. Didn't offer me any assistance. Never said you know if you need help take my office number, they can talk to you and let you know what going to come forward. They never gave me anything. He just said I'll see you in the office next Monday. That really bothered me. That was a really emotional time. I'd never known anybody at that time that was diagnosed with breast cancer so I, you know you automatically think the worst.

On the other hand another participant was grateful how she was told she had breast cancer in a different manner:

He said I got the report on Friday, but I didn't want you to worry about it all weekend because there was nothing you could do about it so I decided to call you on Sunday night because tomorrow on Monday we can start making appointments and do something about it. I was okay with that and thanked him for that and continue to thank him every once in a while.

As described above, interpersonal influences could have a paradoxical dimension. Some of the participants weighed the good and the bad in regards to interpersonal influences as they assessed interpersonal influences:

My support team was my former husband John and a girl from high school Denise. The reason I chose Denise was because she is very loud and bossy and is not afraid to tell someone off if she feels they're not being effective. She was wonderful and they helped me through that and were my ears that I might have

missed something on the downside she betrayed the confidence and told everybody at work before I even had a chance to tell people that I had breast cancer. She immediately called and ordered like 50 pink bracelets and she thought she was doing this wonderful thing and I was like, “Denise I only needed a chance to...” Her good kind of balanced off with the bad kind of thing.

### **Stages of Negotiating Emotional Order**

From the data a five stages latent process of negotiating emotional order consisted of: 1) Losing Life Order, 2) Assisted Life Order, 3) Assuming Life Order 4) Accepting Cannot Control Threat, and 5) Creating Emotional Order. This latent process also had a cyclical property as well; this was evident from the data collected from participants who had experienced cancer more than once or were being tested for cancer recurrence. It also seemed the first time a breast cancer survivor went through the stages was the most emotionally disturbing. This may have been the case as when faced with an additional cancer diagnosis or when being worked up for a subsequent abnormality, the breast cancer survivor had already self-educated themselves previously, had lived experience and were aware of emotional modifiers. The basic outline of the five stages of the theory is illustrated in Addendum L. The properties and sub-properties of each of these stages will be discussed and described in detail in this section.

#### **Stage I: Losing Life Order**

**The Threat of Breast Cancer Becomes a Reality.** Losing order encompasses two properties of disorder: losing emotional order and losing physical order. Upon finding an abnormality and then confirming breast cancer the breast cancer survivors feel loss of control of their bodies and this causes emotional duress. This phase marks the survivors’ first sense that cancer cannot be controlled; during this time breast cancer survivors try to figure out “why me?” and make sense out of the diagnosis. Loss of

emotional order is represented by feelings of sadness, anger, immediacy, loneliness fear and uncertainty. This narrative described these feelings:

I was angry for a long time because I really took good care of myself. I didn't think that I deserved it. I come from a family where there is a lot of alcoholism. I have a brother that is a drug addict. A crack head who is healthy otherwise. My sister is a recovered alcoholic who is healthy otherwise. And I always exercised, ate right. I don't smoke. I drink socially. And I get sick with cancer. And I didn't think it was fair. I didn't want anyone else to have it. I'm not saying I wish my sister had it or I wish my brother had it. But when I would go through the feelings of I am the only one in my family that has a history of breast cancer. There is no other breast cancer in my family. Ever. And I was pretty much the one who took care of myself. I was really angry because you start questioning what does it matter? What does it matter if I take care of myself? You know, you can get sick and have no control over that anyway.

The evolution starts when the breast cancer survivor finds an abnormality and climaxes when the survivor enters formal treatment within the healthcare system and places physical control into the hands of healthcare professionals. This period is a time of emotional chaos and decision making. The breast cancer survivors seek information aggressively and take the decisions they make very seriously, a matter of life and death. This is illustrated by the following statement:

But it spread. The doctor told me the breast had to be removed. And that kind of flipped me right out. I kept thinking what do I do, what do I do, what do I do? It was a horrible thing. I thought to myself, is this the way I am going to die? You know because you hear so much about breast cancer.

**Taking Matters into Own Hands.** During this time period the realization of the threat of breast cancer disrupts emotional order with intense fear and uncertainty of the future. Unfamiliarity with the experience of breast cancer adds to the feeling of uncertainty and causes the breast cancer survivor to seek information from the Internet, popular literature, media and from others who have experienced breast cancer. The breast cancer survivor has a sense of intense immediacy to gain knowledge of what is next to

come. Unfortunately, their need for immediacy is often not met by the healthcare community, so they take matters into their own hands and act. They feel as though by acting they are doing something to oppose the cancer. This struggle was illustrated by a participant's interview statement:

Well when I got home, I Googled, I looked online. I Googled breast cancer and Syracuse, New York. The first thing that came up was the breast care center at upstate. My thoughts were that if I have breast cancer why would I not want to be treated by the breast care center? It seemed like a natural fit for me.

So I at that point I was trying to contact my GYN office to get me an appointment with breast cancer center. They were in the process of moving offices. I couldn't get through. I get voicemail, leave a voicemail. She wouldn't call me back. The following day I called again and again the nurse didn't call me back. Finally a receptionist there said you know *I* will call over and see if I can get you an appointment. The receptionist called back and said no we can't get you an appointment; you have to be referred by the surgeon who did the procedure. So I called the breast care center myself and they've actually made an appointment for me. They made an appointment for the following week, which was something that my GYN office said that they could not do.

The breast cancer survivor often makes decisions and acts on her instincts to placate the immediacy that she feels prior to starting treatment. Participants in this study described of having been told they have breast cancer and having to decide what treatment to pursue and what providers to contact. Several participants took matters into their own hands and took unconventional methods to obtain the care they desired. One participant shared how she orchestrated getting her mammogram done early:

I did go to my gynecologist, told him it was why I went for a mammogram, nothing they couldn't see anything. I said, "Well it really sucks," and I said, "But I can feel something," and they said, "Well why don't you go back in six months." Well this thing kept bugging me and I really could feel it, it was like this hardness from the inside. I walked into the imaging center at the time and I said I need to have this done, I just need to have this done I have an appointment. What I kind of did was I said I know I'm scheduled today, but I knew I wasn't. Yeah and so I kind of just said, "I know I'm scheduled today, maybe there's a paperwork error, but I know I'm scheduled today," and whatever so I lied and they said, "Okay well there must be some confusion somewhere, but yeah we can

get you in if you can wait about a half an hour,” I said okay. There it was it had been so small three months before that it wasn’t being picked up on the machine. Apparently it has to be a certain size and waiting that three months it had gotten a little bit bigger so they could see it and that started my process.

**Concealing to Maintain Family Order.** Many of the participants voiced that this time period was difficult, as they had multifaceted family roles as wives, mothers and children of parents of their own. Even though the diagnosis is subjective the participants talked about the additional emotional turmoil they experienced because of the roles that they play in the lives of their loved ones. The participants expressed a strong sense of trying to protect their loved ones from the fear of cancer. In order to protect them from suffering, the participants began to hide emotions for the sake of family members. One participant expressed the need to conceal her diagnosis initially:

The big thing. When they first told thought when they told me I had it was how was I going to tell my family. And that was a hard thing for me. I told one friend, I didn’t tell my parents or my kids for like 2 weeks. I didn’t tell anybody but one friend.

Another participant also talked about family and the busy lifestyle that having children at home creates. This active role in the family also causes concern:

Well, I think you're so panicked when you get a diagnosis. At least I was. It was the last thing from my mind. I had three children. The youngest was in high school. My one son, I'm sure, was still in college. All of a sudden, your life comes to a screeching halt, and you have to completely alter your general mindset to accept this diagnosis and to figure out how it's going to affect you.

The participants also voiced continuing or attempting to continue on with their family roles. The women continued to work, care for children and maintain their households. Many voiced that they didn’t have time to let cancer get in the way emotionally as they were too busy with family and work responsibilities. The participants spoke of emotional duress when they saw their families react to their illness and chose to

protect their families by concealing their emotions. One participant talked about why she concealed her emotions:

The emotional impact it had on my family was horrible. That I felt like I had to be strong for them. I wasn't allowed to have weak moments because every time they would crumble. You could see the hurt on their face. I couldn't stand to see them hurt like that so I had to be strong for them too. I would keep a very strong face. I would not show any emotions about being sick.

### **Summary**

The first stage of the Theory of Negotiating Emotional Order is Losing Life Order. This stage has three sub categories: The reality of breast cancer, taking matters into own hands and concealing to maintain family order. The purpose of this stage is for the breast cancer survivor to evolve emotionally and move into the second stage, Assisted Life Order, in which they enter treatment for breast cancer.

### **Stage II: Assisted Life Order**

Assisted life order is the second stage of the Theory of Negotiating Emotional Order. During stage two, the breast cancer survivor enters treatment and focuses all of her energy into physical well-being. At the same time, survivors entrust their life order into the hands of healthcare providers and rely on social support to carry them through the time that they are in treatment. During this time, the breast cancer survivor is kept physically and emotionally occupied with the routine of appointments and treatment. Additionally, they do not feel well physically due to surgery and treatments. During this stage, breast cancer survivors may feel as if they are doing something about the threat of cancer by actively taking treatment. At the same time, the breast cancer survivor is

becoming familiar with the diagnosis and to avoid feelings of loneliness, seeks others breast cancer patients with similar experiences.

**Treatment as a Sanctuary.** Surprisingly, although treatment is a physically draining endeavor, the breast cancer survivors voiced it was a time of respite when they focused on routine and physical well-being rather than the emotional disruption that had occurred. One of the participants talked about becoming robotic during treatment and going through the motions:

Yeah and at that time going through the process that was my job. My job was to accept what was going on. I couldn't wish it away. My job was to show up every day and be as healthy as I could, do radiation, do the medication, be aware of any body changes. It was a whole job description in my head. That's what I think when I say acceptance. I had no other distractions going on and so I accepted the diagnosis is, well why not I mean somebody has got to. Like I said there is eight women and nobody else I know in that group of eight has cancer, well I guess it's me. Just I think I became robotic in some things parking the car, walk into radiation, giving them my cd to play it, having them blast it loudly, assuming my position, waiting for the machines to come closing my eyes because I didn't want to see the machines. Okay you're done get dressed, get my CD walk out, it become robotic.

During this phase, the women were often consumed with treatments of surgery, chemotherapy and/ or radiation. Often they expressed not feeling physically well and focused on just getting through the treatments. Routine visits for treatment also allow the breast cancer survivor to fill time and to place the emotional aspect of breast cancer "on a back burner". The participants stated they felt proactive and protected while under the frequent care of healthcare providers. This participant's narrative exemplifies the feeling of being assisted emotionally and physically by healthcare providers: "While you're getting it, you think you're doing something to kill off any additional cancer that the

surgery didn't get. You have certain protection. You have protection while you're taking chemo”.

**Lonely in the Breast Cancer Experience.** Additionally the breast cancer survivors verbalized feeling lonely, despite having much social and family support. They reported feeling lonely in their experience and purposively sought other women who had endured breast cancer for emotional support. Breast cancer survivors in this sample, sought emotional support from formal and informal support persons. The participants also discussed a phenomenon where other breast cancer survivors would approach them after hearing about their diagnosis and come to their assistance to provide support. The importance of this camaraderie was evident in this narrative:

Oh my emotions were all over the place. Because I didn't know people that have been through this. Of course initially I was completely put down. I thought it was going to die. And it wasn't until having conversations with people and people came out of the woodwork. People that I had known that I didn't know that had cancer who shared their stories with me.

Some of the breast cancer survivors also voiced that support groups were a sounding board, where they were free to talk about common concerns. During stage two the realization of the need to have a connection with someone who has experienced breast cancer begins. Some women use formal support groups for this need and continue to use them after treatment is completed. Camaraderie is illustrated in the following representative quote:

The other thing is just the plain camaraderie. We get together. We can talk about, you know, I've got this pain in my ankle. I don't know. It's not going away. I think I've got ankle cancer. Your family will say, oh, you think about that cancer all the time, but the other women who've been there will say, yeah, I know what you mean, and it's probably okay, K. so we can talk about those things that you can't necessarily talk with your family, and that's been a big thing.



However in some cases the unsolicited support also caused emotional duress and fear. In some cases, the participants reported that if they felt they had reacted emotionally, this upset them two- fold: one they became scared and two they felt guilty for their response. The fear and emotional response to unsolicited assistance was expressed in one participant's narrative:

I've seen a girl, that didn't have no breast on one side and one on the other. And she had a prosthesis breast and it kept going to the side. And that was like freaking me out. My God, my God. And this lady. I feel so bad about this. This lady volunteered. She was at the hairdressers and my friend N. She was telling her about me. And she goes I'll come over and talk to her about the normal saline implants. I love my breasts. So she came over and she showed me her breasts with the normal saline implants. Right. Well the breast part looked gorgeous, they looked real. And then I saw this white, well red scar across the top of her chest. Where they cut it out. I don't know who did the job. I freaked out on her. I started crying and everything. Ooohh my god, I didn't even see her breasts. I mean I was more focusing on that huge scar across her breast. I cried. I never saw her again. I feel terrible what I did to her. I tried to be nice but I thinking of all the stuff that was going to happen. I said oh my god, oh my god.

### **Summary**

In summary, Stage Two of the Theory of Negotiating Emotional Control, Assisted Life Order has two subcategory dimensions: Treatment as a Sanctuary and Loneliness in the Breast Cancer Experience. In both of the dimensions of treatment as a sanctuary the breast cancer survivor seeks assistance to help herself physically fight breast cancer; this is a temporary emotional respite. In Loneliness in the Breast Cancer Experience, breast cancer survivors start to build a more permanent emotional resource to assist them on a long term basis. Although seeking camaraderie is helpful in some cases, seeing or hearing too much too soon can increase emotional distress and cause fear.

**Stage III: Assuming Responsibility for Life Order**

When the breast cancer survivors leave treatment, there often is a feeling of loss and confusion at the end of adjuvant care. The survivor has proximate and ongoing contact with healthcare providers while in treatment; many survivors find emotional fortification and understanding from this frequent contact with what they feel are credible authorities. While in treatment, the breast cancer survivor is actively fighting physically and emotionally distracted. After adjuvant treatment ends the breast cancer survivors must remap their lives and begin to strive for a new normalcy in their lives. The threat at this point changes from the diagnosis of cancer. With the fear of recurrence, the breast cancer survivors must revisit their own mortality. These feelings can cause loss of emotional order.

**Remapping-Where do I go?** At this point, the breast cancer survivors reported a cutting point, a crossroads and making a change in thought process. They become autonomously responsible for their physical and emotional well-being. This is a sharp contrast to their behavior while in treatment, where they live day to day and do not think about the future. This was depicted by one participant's narrative:

Just talking and kind of remapping what we have done and where we are going. Any questions we needed to ask the doctors or anything. Kind of putting it more into concrete form and saying get through it. Let's go the mile.

Once treatments end, survivors must take the wheel and navigate into their life and the future. It does appear that this cutting point is an emotionally charged timeframe: the temporary sanctuary of treatment ends and many survivors feel the need to take subjective responsibility of their emotional order. The following narrative depicts this timeframe:

I remember a time feeling...there was like a deep and I think it was probably right after radiation. I wasn't going to be seeing anybody for a while. I think there might have been that one radiation follows up or something and I wasn't going to be seeing the doctor for maybe like two months and I wasn't going to be seeing my oncology for probably that same two months. I remember feeling that void after the treatment of like I'm really free floating out here. I'm on my own here and I remember that being a very awkward time, a very unsettling time. Though I knew I had my general practitioner I knew I had everybody out there, but it was just like and I remember they had like applause and a diploma when you're done with radiation. I walked down there, I had mixed...I was like light headed, "Yay I'm done." No more assuming the position, but I actually remember feeling very, very alone like, "Okay I've gotten through this now where do I go, what do I do?"

Remapping is a dimension of assuming responsibility for life order. While in treatment, the breast cancer survivor's needs are met by others: family, friends and health care providers. After treatment ends, survivors must reach inward and begin to claim emotional order. Breast cancer causes the breast cancer survivor to re-map their lives temporarily and for some their life focus while in treatment is fighting cancer. At the end of treatment they must start living their lives beyond breast cancer and they often are faced with fear and uncertainty.

**Getting on with Life-Moving on from the Fear.** During stage three, the threat changes from the fear of the diagnosis of cancer to the fear of cancer. The fear of cancer can be recurrence of breast cancer, occurrence of a new cancer and/or cancer metastasis. The sample that was interviewed consisted of participants who were from three months to twenty-four years post treatment. Despite the variation of time since the ending of treatment, all of the participants discussed levels of fear of recurrence. The process of beginning to move on from the emotional effects of the diagnosis of breast seemed to begin shortly after the end of treatment.

After the participants finished treatment for the physical aspect of breast cancer they began to work on the emotional aspects of the diagnosis. They moved on from the

treatment aspect of breast cancer and began living their lives and placing the diagnosis into their past. A participant, who was three months post treatment, discussed this phenomenon:

Last week I just had my tissue expander is changed for my implant surgery. So that was the last stage in this step of the process. Now I kind of feel like it's time that I can finally start to move on with life.

Several of the participants stated it was not so much an inherent process as an active decision to take control of their feelings of fear and move on. In this stage, the turning point is the active decision to leave breast cancer in the past and focus on the present and future. Another participant, who was thirteen years post treatment, discussed this decision: “Probably after I had my two breakdowns. I told myself, I have to make a move here. You can curl up in a ball and die or I can move on. I started moving on”.

The feeling of fear is an obstacle that emotionally paralyzes the breast cancer survivors. Fear of recurrence withholds the breast cancer survivor from being present and achieving post traumatic growth in their life. Fear seems to be initially intense then becomes manageable over time for many. Several women noted the recurrent fear abated somewhat after the first year and more so after five years. One participant, who was just three months post treatment, spoke about the intense feeling of recurrence at the point she was currently in her disease trajectory:

Right now I can't picture this as a memory because I'm living in it still. 10 years from now if I don't have recurrence... maybe. Maybe it will be such a small part of my past, that it won't be the first thing I think about. I can't necessarily answer yes or no. But sure I would really hope for that day. I feel a lot uncertainty right now.

Another participant, who was also thirteen years post treatment, discussed her active decision to stop cancer from causing intense fear: “I have decided this is not going to run my life. Because I did let it get away with this for the first 2-4 years. Like I said everything that happened it was cancer. More cancer in my mind”.

The fear of recurrence also can return many years after the completion of treatment. This is especially true if the breast cancer survivor discovers new symptoms or abnormalities that lead her to believe the cancer has returned. Often waiting for the results of diagnostics cause extreme anxiety and fear of recurrence. One participant, who had breast cancer and was diagnosed with a different breast cancer a few years later in the other breast, struggled with a scare the day before her interview. She had been experiencing pain in her head and was fearful of a recurrence of cancer in her brain. She had actually cancelled her interview early the day before the interview, and then re-scheduled the interview after receiving the results of her brain MRI in the afternoon:

I had my obituary written. I was calling my kids home for the Holidays. I was having major head surgery. That's where I was. Certainly unfounded, but obviously that's where I'm going to go. Am I afraid of death? Not really. What I'm afraid of I think (*starts to cry*) is the whole process of cancer. How it takes a person, physically, appearance-wise.

This participant stated that, even though years had passed since she had ended treatment and had felt she was in emotional order, she noted she felt unsure that perhaps she had been distracting herself from feelings of fear and not dealing with these emotions. She shared feelings of emotional turmoil while waiting for results of a MRI of the brain to rule out potential brain metastasis that caused her to regress to Stage One: Losing Life order.

I don't know. At times I did, at times I didn't. I was like a Geiger counter going one way or the other. Yesterday, keeping busy, I kind of kept myself in control I guess. I control other things, yes. Yes. I took action. I called Ray. Got information from him. Okay sure, I'll do meditation. I love Andrew Weil. I picked up his *Spontaneous Healing* book. "Okay, I'll read him." I guess those are things that I did take control of. So I guess I was in control. That answers that.

Yesterday when the doctor called to say everything was okay, my best friend Suzanne was on her way over. Right after I hung up the phone, she knocked on the door and came in and I was totally out of control. I don't think I have ever been so emotionally overwrought. I don't think I've ever cried through any of my cancers—any of the things I've gone through. I cried yesterday and I know they were good tears, they were relief and gratitude and all those things. I could've been on the floor in a hump if it wasn't for her walking in the door.

This is an example of how a breast cancer survivor can regress in the process of negotiating emotional order, indicating the process has a cyclical dimension. This participant went from created emotional order to assisted life order due to the diagnostics and emotions caused by the fear of cancer recurrence. It is important to note this was 8 years after she had completed treatment. The difference for a long-term survivor is that many such women have recognized modifiers in place and know where and when to seek assistance. Additionally in this case the survivor regressed to the first stage and then moved very quickly through the subsequent stages and back into the Stage V and began to again to create emotional order.

**Summary.** Stage three: Assuming responsibility for life order has two dimensions that breast cancer survivors partake in: 1) Re mapping-Where do I go? And 2) Getting on with Life-Moving on from Fear. During this time the threat changes to fear of recurrence of cancer. Initially right after the end of treatment there are intense feelings of uncertainty caused by the fear of recurrence. The breast cancer survivor in this stage makes an active decision to put the feeling of fear of recurrence in order in order to move towards emotional peace and is able to move to stage four: Accepting Cannot Control Cancer.

**Stage IV: Accepting Cannot Control Cancer**

Uncertainty of the future also causes emotional distress for breast cancer survivors. The threat of recurrence of cancer is an aspect of their lives that breast cancer survivors cannot control. The reality that no one can control their own mortality or cancer, is an aspect of the emotional trajectory that the breast cancer survivors struggle with initially. Once breast cancer survivors make this realization, they can then subjectively gain order of their emotions. This is an autonomous action as no one else but the breast cancer survivor can complete this task. One participant spoke about this decision: “There are things that I can change and there are things that I am powerless over. It’s distinguishing and I do have control over what I’m thinking”.

**Fearing Recurrence.** With the conclusion of treatment, the participants spoke of feeling relief and uncertainty of the future. Although they know for sure the cancer they endured did not kill them, they also have no guarantee that it will not recur in the future. They also feel when treatment ends there is no sure way to keep the cancer from coming back. Often times the fear of recurrence affects their daily life initially, until they set cancer apart from living their present life. Often breast cancer survivors accept cancer as a fact of life, or if they cannot, they distract themselves with activities of daily living, or compartmentalize these unpleasant feelings to the “back of their minds”. The participants are acutely aware that cancer can occur thus never feel safe. Subject Ten discussed why the fear of recurrence never goes away:

We've had women in the group, a very good friend of mine in the group, who had breast cancer 18 years ago, had a recurrence, and died. We know that can happen, so we never feel safe.

Breast cancer survivors in this sample often stated they were plagued with reoccurring thoughts of cancer for the first five years post treatment. The women also stated that these feelings were most intense during the first year post treatment. Several of the participants stated the turning point occurred when they realized they could not control cancer or their feelings, and thus accepted order versus control. Three of the participants had experienced recurrence and one was diagnosed with bone metastasis. Common to these women was the feeling that they knew the cancer would come back. Interestingly, despite the recurrence, these women voiced they were at peace emotionally. As the threat of recurrence was no longer an issue, they had accepted their mortality and were living in the present day. A participant reflected on this: "We'll all go some day. It's just my time might come sooner than expected. A part of life".

**Order versus Control.** Although the breast cancer survivor attempts to control her emotions, she often will come to the realization that she can keep her emotions in order rather than control them so that she can move on in her life and get serenity with the past diagnosis of breast cancer. Once the breast cancer survivor realizes that there are aspects of her life that she can control and other aspects she cannot control, the breast cancer survivor moves into stage four: Accepting Mortality. This participant narrative exemplified this part of the process:

The fear of losing control because you don't have control anyway. Don't be afraid. That is what I add to this. Don't be afraid because there is nothing to fear. You don't have control anyway. We could walk out in the street and be killed by a crazy person wanting our purse. We have no control over that. I go anywhere. I do anything. Somebody asks me to go I go. Life is too short. You have to live it while you can. Probably 3 or 4 months after I was done with treatment and I felt like I was going to be OK. I started feeling better. Getting some strength back and it didn't kill me. I really started feeling like if I can do this, I can do anything.



Just do it. Don't think about it just do it. And there is nothing to be afraid of. My father told me when I was a little girl, and this is what gets me, M. do not worry about things you do not have any control over. It will kill you. Stress will kill you. You can't do that. And now because what I went through I have no worries over anything I can't control over. I know it is crazy.

**Living with Reminders.** Although gaining realization of their own mortality, living with reminders forces the breast cancer survivors to cope on a daily basis with the fear of recurrence as they are reminded by physical and cognitive aftermath of breast cancer. Additionally, diagnostics and health care visits also can illicit feelings of fear. Breast cancer survivors also voiced that breast cancer or cancer awareness activities in the community and media also trigger feelings of fear.

**Physical Reminders.** Scars and body changes after breast cancer serve as daily reminders of the ordeal that the survivors went through. The participants voiced that they are constantly appraising themselves for signs of recurrence. Pain often was a trigger that put the breast cancer survivor into high awareness and caused fear of recurrence. Often time it is physical symptoms unrelated to the breast cancer that can trigger feeling of emotional loss of order: "I worry about it all the time. Every ache and pain I have. When my bones hurt I wonder if it is bone cancer. Every time I have to have a mammogram, I pray it's not there".

**Body Image.** Scars and breast deformities also were daily reminders of the breast cancer ordeal. Often times the breast cancer survivors spoke about bathing and looking at the scars in the mirror. Seeing the scars and body changes triggers unpleasant feelings. A participant expressed her feelings about the aftermath that the surgery left her:

They caved in right there (points to area on breast). I never let them finish it. The nipple and everything. One I was devastated how they did it. They put my

stomach tissue, my navel on my breast here. Why do they do that? I'll show you. I have no belly button, they made one. Up here is the navel. I don't know what they were going to do. I was so upset I cried my eyes out. I look at myself naked in the mirror, just the way this has all been done and I cry. Well I keep it to myself. But when I take off my clothes. I undress and I look at the mirror I cry. Because of what happened, you know. I don't think about it but when I talk about it you cry. I try to block it out of my mind, not think about it. You know what I mean.

**Diagnostics.** Preventive diagnostics often generated reminders and emotions of fear of recurrence. Unanimously this sample talked about anxiety with breast exams, mammograms, blood work and more so with the wait time to find out results. During these timeframes, the participants spoke of intense fear of recurrence and expressed relief if the exam was considered normal. One participant talked about having tumor markers more than twenty years ago and the immense stress it caused her:

That was the worst thing of my whole cancer experience, I think, were these tumor markers. I would be so nervous when I went in for the checkup that I could hardly control myself. I did want to know, but I didn't want to know what the number was. There was only once when he actually thought that there might be something going on. I think maybe it had gone up. Twenty-five was the top, and I think I was 30-something, so I wasn't really high, but it just looked a little too much. I know I questioned him about it, and he said, "Well, we'll wait until the end of the summer." This might have been in May or something. He said, "Well, you know, we'll wait until the next three months, and we'll see how it is, and if it's high then, well maybe we'll start looking." So casual, but there wasn't anything else he could say. Oh, it was terrible. It was just as I said. I was just a nervous wreck, and every time I thought about it, I just had to put it out of my mind. I just had to say, "Well, they're not going to do anything this summer."

**Society Cancer Awareness.** Many of the participants in this sample were very aware of cancer and felt that cancer awareness activities and the media during October breast cancer awareness month also triggered reminders of their ordeal. One participant described these feelings:

They have the pink month, October month, Yeah. Interestingly, some of us have a hard time with that because it's constantly in our face. You turn on the television and there's a story about some woman having breast cancer. She's walking, and she's got her pink on, pink, pink, pink. Buy this toaster, this pink toaster.

Breast cancer benefits and community activities also caused emotional distress for some of the participants. Some of the participants stated they cannot attend functions geared for cancer awareness or benefits. To deal with these triggers the breast cancer survivors may avoid these types of functions. One participant stated that she no longer attends cancer awareness events as it triggers feelings of depression and is a powerful reminder of her past experience:

I went for the relay for life for three, four years for his daughter. But you know it was for T. nobody even really realized that I went through a lot. And then I thought about it, and then I said these people walk, of all the people that died. It's so depressing. I'm thinking, Jesus I could have been that. You know what I mean. And then I think of all the people surviving that are happy and stuff. And I remember this one lady, they took a picture she was so happy that she fought cancer and she is gone now. You know what I mean. So to me, I don't want to go to that because it is a constant reminder of what you went through, one. Two, somebody that was happy thinking they survived it, is dead now. You know what I mean. And all of the people you lost. I can't do it. I just want to forget about it. I want to just, like block it out of my mind.

## **Summary**

Stage Four, Accepting Cannot Control Cancer, has three dimensions: fear of recurrence, accepting order versus control, and living with reminders. In this stage, the breast cancer survivor makes an active decision that she cannot control cancer. By doing this, survivors accept they can have emotional order rather than emotional control as the threat of cancer recurrence is perpetual and they often live with daily reminders of their experience. The way that the survivors deal with daily reminders varies and is how the breast cancer survivors move to stage Five, Creating Emotional Order.

**Stage V: Creating Emotional Order**

Once survivors accept the fact that they cannot control their mortality and cancer, the breast cancer survivor creates social order to protect herself emotionally. Breast cancer survivors protect themselves by controlling their actions, compartmentalizing negative feelings, using social comparison and or engaging in planned helpfulness. During this time, survivors move from living with cancer as a considerable part of their lives to living with cancer as a diminutive part of their life. One of the participants who had finished treatment twenty four years earlier stated:

I had gotten to the point where yes, I knew I had breast cancer, but it was just not something that ever entered my daily life really. It wasn't intruding on the rest of my life. I was just going along, living my life and doing ordinary things. I realized that I wasn't even thinking about the breast cancer.

Although reminders often trigger fear, the survivors often use methods to create emotional order, to find balance and not allow feelings of fear to overcome them. Breast cancer survivors are acutely aware that their actions do not guarantee that cancer will not return, but in this stage the breast cancer survivor wants to maintain a status of being healthy, both physically and emotionally. One participant communicated this: "What work do I need to do. I am a survivor and want to be a survivor for a long time".

**Compartmentalizing**

Inherently, human beings have emotions, and one of these emotions is fear is in response to a threat. As the threat of cancer recurrence has a perpetual quality in women who have been diagnosed with breast cancer, the emotional aspect of cancer recurrence is long-standing. In stage five the breast cancer survivor becomes cognitively aware of these emotions. The emotions are there but the breast cancer survivor puts them away.

Since she cannot fully control their emotions, the breast cancer survivor will often compartmentalize negative feelings of uncertainty and fear to achieve emotional order.

In order to emotionally protect themselves, several of the participants spoke about triaging these emotions to the back of their heads and putting these feelings away. One participant illustrated this: “It’s probably because I pushed it to the back of my head because I don’t want to deal with those emotions”. In the case of living with reminders, the breast cancer survivors’ emotions may not be able to be suppressed. When this happens it appears from this group of participants the breast cancer survivors use modifiers, increase their activities or regress into previous stages.

### **Controlling Actions**

Once the breast cancer survivor has accepts the fact that there are aspects of her life she can control and there are aspects over which she has no power, she will begin to create emotional order. Having control over parts of her life allows the breast cancer survivor to have emotional order. Survivors decide they may not be able to control cancer nor can they control fear of recurrence, but they can control their actions. During times of emotional distress they also may increase their attempts to distract themselves from their emotions. This increase in activity may be temporarily increased with times of stress, as in this example of one participant reflecting on her actions in response to emotional disorder during and after a cancer recurrence scare:

Yesterday, I had just ordered some new paint. I had all these tubes of watercolor and I pulled out an art book and the paper. I haven’t looked at what I did yesterday. I know it’s got to be hideous, but it was occupying my mind. I cleaned house yesterday. I had from 10:30 until 4:00. I threw out ten pairs of shoes yesterday. It was like cleaning house. It was like, “I haven’t worn those since I

retired from teaching nine years ago. Why is that taking space in my closet?" It was a little lethargic and therapeutic to go through that yesterday.

Controlling other aspects of life in regards to diet, preventive screenings, weight control and stress management was also evident in this sample. Often times the participants talked about eating low soy foods, low fat foods and organically to help discourage cancer recurrence. Also they spoke of participating in screening methods such as mammograms, despite the unpleasant feeling they were reminded of while waiting for results.

The participants in this study also discussed weight control and striving for a healthy body mass index as it is recommended to ward off recurrence. The breast cancer survivor may also question if her actions will have any effect on her chances of preventing recurrence. One participant questioned if her actions of trying to lose weight really mattered:

I remember I was doing my own research sitting there looking at people going, "Okay, I can accept me, yeah I got a lot of fat cells." There was a lot of cancer trapped in there, I got that. But everybody else that came in there and then when you would do breast cancer walks afterwards and I did those with the ABC Group. Now when I go the ABC Group I still do this. I look around and I'll see like maybe one or two people that are extra round. That whole bullshit thing about, "Well, you're, we'll it's because of obesity." Well, yeah that's a contributing factor but what about these thin people? What's bringing on their breast cancer? What's triggering their breast cancer? It's environmental? What is it? Is it genetic? What is it?

Several of the participants talked about complementary therapies and using herbal remedies in addition to their medical regimes. Additionally, stress reduction methods of meditating, leisure activities and counseling were also used. Often, after the breast cancer survivor feels well, she redefines the actions in which she participates. Survivors express themselves by participating in activities that they enjoy or have wanted to experience, but

did not have the courage to do so prior to diagnosis. The following passages exemplify this phenomenon:

I forgot to bring this up and I think it is important. I am not afraid of anything anymore. I jumped out of an airplane. I did. I have done things. I have no fear anymore. And it is because of my experience. Nothing scares me. I don't understand it. I can't either. My husband was not happy he wouldn't go with me. I did when I was younger then I just put it in the back of my mind. I ran into my cousin who is a professional jumper. And I said I want to go jump out of an airplane. He said we'll do. We jumped tandem. It was incredible.

Another participant described a similar phenomenon:

The second cancer after that I got my pink ribbon tattoo on my leg. I've gotten certified in scuba diving. I've parasailed with my son out in Utah. I pretty much get out of the boat and do what I want to do. I kind of look at every day as a risk of some sort. You walk out your door and you don't know where the day is going. I pretty much do what I want to do. If I want to do something, I'm going to do it. That's pretty much how I live my life right now. I may even drive myself crazy again too with everything I do, but I love my art, it's very therapeutic for me when I was sick.

Breast cancer survivors also talked about controlling their family roles and home environment. Once the breast cancer survivor accepts that she cannot control cancer, she often will focus on other aspects of her daily life that she can influence. The breast cancer survivor may do this by creating a household routine, children or family activities. A participant discussed controlling daily life:

Just my philosophy on life. I don't know. It's weird. Something's you can't control if you can't control it I has to be happening for some reason. You got to go with it and deal with it and make the best of it that you can. Other things in your life you can control, it's not like it is happening. When you control it the way you want. Daily life, you tell the kids go pick out what you want to wear. No mom you can do it mom just because I have done it for so many years I still control it. Just the little things like that. I don't know. I probably control as much as I can.

Distracting self with other aspects of life also is a way that breast cancer survivors create emotional order. By immersing themselves back into their daily routines of work, marital, household and family roles survivors limit the amount of time they have available to think about the fear of recurrence. This is similar to using activity to occupy time during the assisted life order stage. One of the participants illuminated the dimension of life business to emotional order:

I think to keep myself involved with work helped me not dwell on the fact I was living with cancer emotionally. I didn't have time. There was no time. When you're married, when you have kids and the work you do what you have to do. You know what, you don't stop. You don't stop to smell the roses a lot of times. But you don't stop to dwell in the situation or to what's occurring. A lot of times I just went through the motions.

### **Social Comparison.**

Social comparison through self-evaluations was another way that this sample group achieved emotional order. Social comparison was evident almost unanimously in the data. Participants spoke often of reflecting on the experience they endured and feeling lucky. While exploring this code the researcher asked the participants what they meant by luck or being lucky. Consistently the participants talked about luck as comparing outcomes as better or worse. For example a participant stated when asked what she meant by having better luck she replied: "Well I was thinking someone maybe had the same surgery as me did better than me". This is an example of a breast cancer survivor socially comparing her experience as worse than another person's experience.

Breast cancer survivors used social comparison as a method to create emotional order by viewing their experience as better than others who had poor outcomes. As a defense mechanism, if the breast cancer survivor views her experience as positive then



she reaffirms she is a survivor. Social comparison enabled the breast cancer survivor to assess her situation as positive and create increased hope thus creating emotional order.

This was evident in a participant who compared her experience with another she felt was worse than her own:

My journey through this process was actually easier than hers was. She had a harder time after the surgery, she had a harder time with the reaction from the chemo, and she had a harder time. So I was anticipating things for myself and my journey seemed to be less, less cumbersome than hers was. At least in terms of a pain, side effects and stuff like that. She actually was off; she wasn't able to work during her whole entire chemo.

### **Benefit Finding**

In addition to evaluating the actual treatment outcomes and evaluating the way that they physically dealt with treatment, the breast cancer survivors also evaluated the entire experience of breast cancer by reflection. The ability to reflect onto the past experience to find benefits and positive outcomes related to the cancer allowed the survivor to make sense of the experience and create emotional order. In many ways the survivors felt all they had endured was worth what they had become due to the cancer. Many reflected back and felt they had gained knowledge of self. Knowledge of self, meaning knowing their bodies, emotions and realizing they had abilities to endure adversity that they had not known before the experience of breast cancer. The breast cancer survivors reflected back in awe of the emotional stamina that they had during adversity and were proud of their accomplishments. This is showcased by one participant's narrative: "It is amazing. Yeah if someone had told me I could write a book, become a massage therapist and learn the body the way I have. I would have said no way".

Many reflected back and felt they gained a better understanding and faith in other human beings, thus improving their quality of life. Additionally they felt more focused in their own lives and felt their life priorities had improved due to their illness. Looking into the future they felt that they were able to assess what was subjectively important to them in their life and worry less about insignificant things. One participant showcased this:

As far as emotional also about the way I look at life is a bit more fine-tuned. Things that bother and wrinkle other people they don't faze me. The things that like people will be, "Oh my god do you believe that he did that?" I'd be like who wastes their time on this kind of stuff. Some things don't bother me that used to bother me. Actually a lot of things don't really bother me. I can't think of an answer right now and I might be able to later, but I can't think of one right now. Emotionally I think I feel things a lot deeper on a different level, but I also feel I understand people better than I ever did as a social worker.

### **Planned Helpfulness.**

"I feel like I know these people. You have been through what they have been through. They don't know it but I know it". This participant's narrative sums up the transparent common bond the participants felt they had with other cancer survivors. In order to create emotional order the breast cancer survivors helped others as a way to help themselves emotionally. Planned helpfulness allows the breast cancer survivor to create emotional order by gaining satisfaction through assisting others. Often the breast cancer survivors employ ambiguousness until they are ready to disclose their survivorship status. This allows them to feel empowered and also allows them life choices. This was a common theme throughout the interviews. Breast cancer survivors planned and decided how they would help others; many were grateful for the acquaintance disclosure and guidance they received early in their disease trajectory and want to pay forward some

type of comfort to others who are enduring cancer. Another breast cancer survivor described, that as result of her illness, she wanted to help others as she had been helped:

I am very open to talk about it myself. I think one of the outcomes is that I would be the first one to be there to try to help somebody out. Where typically I would probably try to stay to myself but now I feel that I want to help other people who are in the same situation that I am and emotionally it gives me great satisfaction to do that. I have actually had one person who was diagnosed since then that I tried to reach out to. I think that emotionally it helps me get through things to be able to.

### **Summary**

In Stage Five, Creating Emotional Order the breast cancer survivors transcend the fear of recurrence by controlling their actions, compartmentalizing negative feelings, use social comparison and planned helpfulness. Although they cannot control their emotions or control cancer, they do control the way they react to emotions and take control of their life actions. Many of the participants shelved their negative emotions in order not to let the psychological aspect of breast cancer interfere in their daily lives. The participants in this study also showed evidence that the survivors can regress between stages of this theory, but after their initial passage through the stages progress forward quickly and resiliently.

### **Meanings Inherent in the Theory**

The meaning inherent in the basic social process of Negotiating Emotional Order is that women who have been diagnosed with breast cancer strive for emotional order by negotiating control of the negative feeling of threats to their mortality, in order to live their daily lives. The process described in the Theory of Negotiating Emotional Order changes as the situation of the breast cancer survivors' changes and as time passes while

the women move from finding an abnormality to the time period after treatment ends.

This process is dynamic and perpetual in nature as the threat of cancer recurrence remains until the end of the breast cancer survivor's life. For some, negotiating emotional order is achieved even when the cancer recurs or with metastasis. Feelings of emotional loss of control can be triggered by reminders after treatment ends. Reminders include: physical reminders, body image reminders, diagnostics and society cancer awareness.

There were cutting points that were evident in the data. Five cutting points that were significant in this population and that was grounded in the data were: 1) Finding an Abnormality, 2) Waiting for Confirmation of Diagnosis, 2) Confirmation of Diagnosis, 3) In Treatment, 4) Completing Treatment, 5) Moving On-Accepting what can control and what cannot control. Different from the cutting points were the five stages of the latent process that emerged from the data: 1) Losing Life Order, 2) Assisted Life Order, 3) Assuming Life Order 4) Accepting the Things Cannot Control, and 5) Creating Emotional Order.

Losing Life Order encompasses the first three consecutive cutting points: 1) Finding an Abnormality, 2) Waiting for Confirmation of Diagnosis and 3) Confirmation of diagnosis. It is important to separate the cutting points that represent times of emotional disorder and the stages of the theory. Assisted Life Order represented the time the breast cancer survivor was in adjuvant treatment. Assuming Life Order is the time period directly after the completion of treatment. Accepting Things Cannot Control and Creating Emotional Order occurred in the time period following the completion of treatment.

There also were modifiers that were present in all of the stages of the Theory of Negotiating Emotional Control. Forces that change negotiating emotional order are emotional modifiers. Emotional modifiers included: interpersonal influences, information, spirituality, and humor. Negotiating emotional order results from the cognitively accepting and assessing cancer and the emotions caused by the uncontrollable threat of cancer throughout all the stages and cutting points of the disease trajectory.

The basic latent process of negotiating emotional order is a linear process that occurs over time. Stage I. Losing Life Control is the first stage where the threat of breast cancer becomes a reality. During this stage the breast cancer survivor takes matters into her own hands and makes decisions about her actions and treatment. Due to the multifaceted family roles the woman may conceal her emotions and illness to protect her family. During this stage there is a feeling of fear and immediacy that causes breast cancer survivors to seek information and assistance to begin treatment.

Stage II. Assisted Life Order is the second stage. During this stage the survivor begins treatment for breast cancer. Some women seek assistance from other breast cancer survivors due to feeling lonely in their experience. During this time, emotions are put on the back burner and the breast cancer survivor feels protected and proactive as she focuses on her physical health. This is a busy time for the breast cancer survivor and she often feels comfort from the routine and frequent contact with healthcare professionals. The breast cancer survivor feels as if they are in a sanctuary during this time.

Stage III. Assuming Life Order is the third stage. This stage begins at the completion of treatment. During this time, the breast cancer survivor often feels lost

because she has become accustomed to routine contact with healthcare providers and feels like she is no longer being proactive in fighting against cancer. In this stage, the threat changes from active cancer to the recurrence of cancer. During this time, breast cancer survivors take the wheel and assume control over their destiny. The breast cancer survivor begins to move on from the active breast cancer experience and to move on from the fear of recurrence as they become more active in their daily lives. At the end of this stage, the breast cancer survivor makes an active decision to move on with her life.

Stage IV. Accepting Cannot Control Cancer is the fourth stage. This stage is multifaceted as the breast cancer survivor recognizes the paralytic emotional effect of fear of recurrence. Additionally in this stage the turning point is when the breast cancer survivors acknowledge that they cannot control cancer but rather can attempt to keep this emotion in order. During this time the breast cancer survivors begin to make decisions and regulate living with daily reminders of their diagnosis that may cause them to lose emotional control temporarily. Reminders include: physical, body image, diagnostics and society breast cancer awareness. Once the breast cancer survivor accepts the lack of control in regards to cancer she can move on to the fifth stage and begin creating emotional order.

Stage V. Creating Emotional Order is the fifth stage. During this stage, the breast cancer survivor begins to create emotional order by compartmentalizing feelings she cannot control, controlling actions, using social comparison to foster hope, reflecting on the experience to find benefit and begin to participate in planned helpfulness.

Inherent in the meaning of the concept of negotiating emotional order is the fact that women who have been diagnosed with breast cancer may incorrectly assess cancer as being controllable and therefore struggle with acceptance and this may hinder them achieving emotional order. The process does seem to be cyclic as evidence expressed from the participants that diagnostics and workups to rule out recurrence cause temporary loss of emotional control. It does seem that it takes much less time to move back into phase IV and V once the breast cancer survivor has gone through all of the stages. When temporary loss of emotional control occurs the breast cancer survivor often will seek assistance and employ the emotional modifiers to gain emotional order. This process also appears to be perpetual in nature as one participant noted the uncertainty if the cancer will recur is lifelong:

The lesson there is we don't know. I don't know. Is it going to be breast cancer? I don't know. I won't know until I take my last breath whether or not it's breast cancer and in that case, I can say call the researcher yeah, it was breast cancer that got me.

### **Summary**

In summary, negotiating emotional order is a dynamic, temporal, cyclic process that women who have been diagnosed with breast cancer endure. This process reflects the variations of behaviors that breast cancer survivors display while attempting to attain emotional order. Participants who feel loss of life order due to a new or pending diagnosis often feel immediacy, will seek assistance and will act on their feelings of immediacy. The common concern of the participants that were interviewed was negotiating emotional order. They did this in order to live their lives with the emotions of uncertainty, due to the fear of cancer.

## ***CHAPTER VI.***

### **Discussion of Findings**

When using grounded theory method, substantial theory emerges from information grounded in the data. In this study, a practical theory of negotiating emotional order emerged as a theory of how women with breast cancer survive psychologically to resolve the main concern of fear of cancer and facing mortality. In this section, the findings of the study will be reviewed in relation to the current literature and the contribution of this theory will be compared to the extant literature.

#### **Relationship of Findings to the Extant Literature**

Minimal studies were initially found in the initial literature using PubMed, CINAHL, PyscINFO, Medline and EBSCHO catalog hosts that examined the process of survivorship from the perspective of breast cancer survivors. Interestingly most of the research that was found pertaining to this study was found in psychological literature. This seemed significant to the researcher as there is a gap in the nursing literature reporting un-met needs. Some of the participants in this study reported that health care providers did not address the psychological aftermath of cancer with the breast cancer survivors during extended survivorship. This was showcased by one of the participant's narrative:

They check my breasts and say I am good to go. They don't want to know. It is my opinion they don't want to know any struggles you have mentally. They want to know how you are doing physically. No blood work is ever done. So other than your mammogram there's no other real contact. The gynecologist probably has the most involvement. Cause they are doing the pap smear test and all that. I think once you're done and out a year you are in and out of the doctor's office in 15 minutes. I really don't feel they want to know mentally what's going on.



Upon returning to the literature after the data was collected and analyzed, one grounded theory study was found that explored breast cancer survivorship (Sherman, Rosedale, & Haber, 2012). Sherman et al. (2102) interviewed 15 women diagnosed with early stage breast cancer ranging from one to twenty years since the completion. In this study, it was not reported if any survivors had experienced cancer recurrence.

The authors used Strauss and Corbin's grounded theory method. Using constant comparative analysis, the core variable identified was Reclaiming Life on One's Own Terms. The initial stage of the process was breast cancer as a turning point and catalyst for change. This was followed by the recognition of cancer being a part of their life, learning to live with breast cancer and creating a new life after breast cancer. The authors reported that they used three levels of coding: open, axial, and selective. Sherman et al. (2012) also used memos and member checking during their analysis which is consistent with Strauss and Corbin's method.

Sherman et al. (2012) reported that breast cancer survivorship was a transformational process that encompassed the time from acute illness through the future. The effect of time on the process was consistent with the findings of the current study. Sherman et al. (2012) spoke solely of the time from actual diagnosis and beyond. A difference that was noted in the current study was that the participants discussed with emphasis the time period when they recognized an abnormality and also the time that the abnormality was confirmed to be breast cancer to be important.

In the current study, the survivors who had endured reoccurrence or were being screened for a recurrence revealed regressing back to the time period identified as Stage

I: Losing Life Order. This cyclic nature of regression in the stages was a significant finding and was found to be a period of time that caused psychological distress. This was different from what was reported by Sherman et al. (2012). The theory model proposed by Sherman and associated expressed only a linear process and did not discuss recurrence of cancer. In the current study, regression in the Stages of Negotiating Emotional Order was found to vary at different times post adjuvant treatment and was this was due to the unpredictable nature of cancer recurrence.

Sherman et al. (2012) also reported interpersonal modifiers that influence the process of survivorship, which also is in concert with the current study's findings. Sherman et al. (2012) identified the period that was immediately post treatment, or transitional survivorship, which was consistent with the current study's findings thus reinforcing Miller et al.'s (2008) proposal that was discussed in the initial literature review.

### **Transitional Survivorship Identified- Stage III: Assuming Life Order**

In the initial literature review, several authors spoke of transitional survivorship or the time that immediately followed the completion of treatment (Lobb et al., 2009; Miller et al., 2008; Rosedale, 2009; Rosedale & Fu, 2010). This time period was found to be emotionally distressing (Beatty et al., 2008; Henselmans et al., 2010). Miller et al. (2008) had postulated that the time period immediately post treatment was significant in the breast cancer survivorship process and coined this time period transitional survivorship. However, Miller et al. (2008) claimed this time period was significant from their observations and experience in clinical practice not from empirical research.

Furthermore, the initial literature review found that no study had captured this time period or had looked at the process of breast cancer survivorship holistically. Sherman et al. (2012) did recognize transitional survivorship in the findings of their study.

In the current study, Stage III: Assuming Life Order was identified as the time period immediately after the completion of treatment when the breast cancer survivor re-navigates and decides her life path. During this time the breast cancer survivor moves on from the fear of recurrence. This stage was identified by the participants as a time period that was emotionally distressing during which several of the participants stated they asked themselves “Where do I go?” The recognition of the phase of transitional survivorship was a significant finding in the current study.

This consistent response during the time immediately after the completion of treatment was also reported in several studies in the literature (Carpenter, Brockopp, & Andrykowski, 1999; Henselmans, Sanderma, Baas, Smink, and Ranchor, 2009; Warren, 2010). Henselmans et al. (2009) reported that the phase immediately after treatment is completed is when the maintenance of sense of control seemed most difficult for breast cancer survivors. Henselmans et al. (2009) explained the increase in emotional distress is due to the fact that personal control is threatened during this phase of the disease trajectory. This is also consistent with the findings that were reported from themes that emerged from interviews reported by Thomas-MacLean (2004) that included leaving treatment left the breast cancer survivors feeling abandoned and lost.

**Redefining the Stages of Breast Cancer Survivorship**

The seasons of survivorship that were reported by Mullan (1985) have become a staple in cancer survivorship literature. As reported in the initial literature review, seasons of survival based on Mullan's subjective narrative include three stages: 1) acute survivorship, from diagnosis to the end of adjuvant treatment; 2) extended survivorship, end of treatment until the survivor enters remission and 3) permanent survivorship, once the survivor is cancer free and returns to physical and psychological normalcy. The current study challenged Mullan's (1985) model of survivorship in several ways.

First, in the current study, breast cancer survivors describe the process of survivorship beginning before diagnosis, with the discovery of an abnormality. This is different from Mullan's (1985) model in which the process of survivorship is said to begin with diagnosis. Second, a new stage that represented transitional survivorship or Stage III: Assuming Life Order was described in the current study as the period immediately following the completion of treatment. Third, Mullan (1985) described extended survivorship as ending once the survivor enters remission. Although the majority of breast cancer survivors interviewed for this study entered remission, several experienced recurrence or had metastatic breast cancer so Mullan's model excluded the process that these individuals endured.

Lastly, in this study extended survivorship appeared to be a continuous state rather than a conduit to permanent survivorship as Mullan (1985) described in his model. Mullan (1985) stated permanent cancer survivorship begins once the person is considered cancer free and is able to successfully return to their normal physical and emotional

abilities prior to the cancer diagnosis. The survivors in this study described extended survivorship to have a perpetual nature rather than being permanently cured physically or emotionally. They also challenged the fact they would return to “normal” This was described by one of the participant’s narrative, “It was a rough road. Trying to figure out who I was, where I belong. Because they say your life goes back to normal, there is no normalcy. I don’t feel I am normal today”.

This finding was significant as many breast cancer survivors may feel the need to feel “normal” due to the extensive publication of Mullan’s (1985) model. The current study may be helpful to breast cancer survivors, as it sheds light upon the actual process they endure from the narratives expressed in the data. As will be discussed later in the paper, breast cancer survivors are found to use social comparison to evaluate their own well-being and look to credible authorities to gauge their personal progress. The use of Mullan’s (1985) model by many credible cancer authorities may prove to be confusing and frustrating to breast cancer survivors who lack the feeling of normalcy after treatment is completed and into extended survivorship.

## **Fear**

Feeling threatened causes fear. Breast cancer is a threat. Cancer triggers emotional distresses of fear due to the uncertainty and potential pain and suffering associated with the disease. Cancer was found to be the most prevalent disease entity that caused fear in the United States (MetLife Foundation, 2011). Additionally the percentage of Americans that fear cancer has risen in this study as compared to results done in 2006 (MetLife Foundation, 2011).

It stands to reason that if the majority of Americans fear cancer, that fear would be prevalent in the population of breast cancer survivors who have faced the threat of cancer. Adding to the prevalence of fear in breast cancer survivors is the fact that recurrence of cancer is a harsh reality. Fear of recurrence was reported by all of the participants in the current study. One participant summed up the feeling of fear: “It’s a horrible feeling, like something runs right through your whole body. Really scary. It’s a scary feeling”.

Consistent with this study’s findings, fear of recurrence was also found extensively in the literature (Arman & Rehnsfeldt, 2003; Carpenter et al., 1999; Gil et al., 2004; Henselmans et al., 2010; Shaha et al., 2008; Sherman et al., 2012; Stiegelis, Hagedoorn, Sanderman, VanderZee, & Buunk, 2003; Wilkins & Woodgate, 2011). Van Den Beuken-Van Everdingen, Peters, De Rijke, Van Kleef, and Patijn (2008) reported that moderate to severe feelings of fear of recurrence were present in 136 breast cancer survivors who had completed treatment. Levels of worry were independent of time since diagnosis (Van Den Beuken-Van Everdingen et al., 2008). This was consistent with the findings in the current study; the participants were three months to twenty four years post completion of treatment and all expressed having feelings of fear. Van Den Beuken-Van Everdingen et al. (2008) also reported feelings of fear of recurrence were negatively correlated with quality of life measures.

## **Control**

The construct of control can be found in the literature in multiple patient populations: breast cancer (Warren, 2010), cardiac disease (Svansdottir et al., 2012),

patients with obsessive compulsive disorder (Kang, Namkoong, Yoo, Jung, & Kim, 2012), diabetes (Hughes, Berg, & Wiebe, 2012), sexual assault (Frazier, Mortensen, & Steward, 2005). The phenomenon of control was found to be prevalent in the breast cancer literature. It was found to be called several terms: locus of control, perceived control and emotional control (Arman & Rehnsfelt, 2003; Astin et al., 1999; Barez, Blasco, Fernandez-Castro, & Viladrich, 2009; Beckjord, Glinder, Langrock, & Compas, 2009; Henderson & Donatelle, 2001; Henselmans et al., 2010; Mehlsen et al., 2009; Tacon et al., 2001; Taylor, 1983; Thomas-MacLean, 2004; Tomich & Helgeson, 2006; Wallston, Wallston, Smith, & Dobbins, 1987; Warren, 2010). In this study, loss of emotional control was an important finding as it served as a catalyst shaping the decisions and actions of the participants. It is also important to note that the disease of cancer, despite major medical advancements and research, cannot be predicted or controlled by any person or action. . Cancer triggers emotional alarms of feelings of loss of control and fear. This is due to the uncertainty and potential pain and suffering associated with the disease.

**Breast Cancer as a Threat Causing Loss of Control.** As reported, the fear of cancer is the most prevalent fear of disease in the United States (MetLife Foundation, 2011). The main concern of negotiating emotional order was found to be significant from pre-breast cancer diagnostic screening for abnormalities thought extended breast cancer survivorship and this was also confirmed in the literature (Mehlsen et al., 2009; Warren, 2010). The perceived feeling of loss of emotional control is in response to the threat of cancer (Leadbeater & Larder, 2008; Svensson, Brandberg, Einbeigi, & Ahlberg, 2009; Wallston et al., 1987). In the population of interest, the threat that serves as the catalyst

causing feelings of loss of control changes within the process of breast cancer survivorship and initiates actions and decisions to restore emotional order.

It was found in the literature and also in the current study that perceived loss of control was intense at the time of initial diagnosis (Arman & Rehnsfelt, 2003; Astin et al., 1999; Barez, Blasco, Fernandez-Castro, & Viladrich, 2009; Beckjord, Glinder, Langrock, & Compas, 2009; Henderson & Donatelle, 2001; Henselmans et al., 2010; Mehlsen et al., 2009; Tacon et al., 2001; Taylor, 1983; Thomas-MacLean, 2004; Tomich & Helgeson, 2006; Wallston, Wallston, Smith, & Dobbins, 1987; Warren, 2010). In the current study, the potential threat upon mortality appeared before the confirmation of diagnosis of breast cancer as the threat of diagnosis of breast cancer. Once an abnormality was found, the threat of the diagnosis of breast cancer causes feelings of loss of control. If the abnormality was confirmed to be breast cancer, the threat became a reality.

While the survivor was in treatment many of the participants reported they felt like they were being proactive and protected from this threat. When the breast cancer survivor completes treatment the risk changes to the threat of recurrence (Arman & Rehnsfelt, 2003; Taylor, 1983; Wallston et al., 1987). This change in the threat causing fear was evident in the current study. The participants' main concern in the current study was to attain emotional control in response to fear throughout the disease trajectory and into extended survivorship.

**Negotiating Order Evolves with Time and is Perpetual.** Perceived control is affected by time, often the desire for control increases with time after the diagnosis of



breast cancer (Astin et al., 1999; Sherman et al., 2012; Thomas-MacLean, 2004; Wallston et al., 1987). This was evident in the current study as the process that emerged had a linear dimension beginning with the detection of an abnormality. Furthermore, in this study the participants created order to psychologically survive the perpetual threat of recurrence that exists in this population due to the nature of cancer. It is important to note that, in this study, many years after the completion of treatment participants still struggled with negotiating emotional control due to reminders of the diagnosis of breast cancer.

**Triggers.** Maintaining a sense of personal control has been found to be a coping mechanism in breast cancer survivors (Arman & Rehnsfeldt, 2003; Astin et al., 1999). Triggers of uncertainty about recurrence persist long after diagnosis and treatment (Arman & Rehnsfeldt, 2003; Gil et al., 2004; Shaha, Cox, Talman, & Kelly, 2008). Furthermore, triggers produce increased self-awareness which is caused by reminders of personal mortality (Carpenter et al., 1999; Shaha et al., 2008; Warren, 2010). In the current study, the participants discussed triggers that cause feelings of loss of control. Triggers that were evident in the current study included physical symptoms, body image issues, diagnostics and cancer awareness activities in society.

Physical symptoms were found to be prevalent in the literature as an antecedent causing fear of recurrence (Constanza et al., 2007; Janz et al., 2007; Jim, Andrykowski, Munster, & Jacobsen, 2007). One participant who was a long-term survivor summed up physical symptoms as a trigger, “I do get little pains. I think they're nerve pains at the site of the incision. For no good reason, but now and then, just kind of reminds me that there's something there”.

Body image issues including taking daily medication, scars and lymphedema cause daily reminders of the breast cancer experience (Begovic-Juhant, Chmielewski, Iwuagwu, & Chapman, 2012; Fallbjork, Salander, & Birgit, 2012). Media and breast cancer awareness activities also serve as daily reminders of the diagnosis of breast cancer (Harmer, 2011; Larsen, Long, Slater, Bettinghaus, & Read, 2009; Mayer, 2012). The daily reminders were elucidated by this participant:

There isn't one single day that goes by that I don't think about having cancer. It's probably because I am still new. And that's because I have those hot flashes that reminds me. I take that medicine every single day that reminds me. Every time I get out of the shower and wipe myself off it reminds me because I see myself

Another time period that also created feelings of loss of control surrounded the anticipation of diagnostics specifically mammograms (Mehlsen et al., 2009, Miller, O'Hea, Lerner, Moon, & Foran-Tuller, 2011). Mehlsen et al. (2009) found mammogram distress was significantly higher prior to the exam as compared to the time periods after it was completed in all of the age groups. Consistent with the current study, mammograms did create emotional distress in women who were awaiting this diagnostic exam to confirm or rule out breast cancer thus additionally validating Stage I: Losing Life Order. One participant shared how she reacted to her scheduled mammogram:

You know what is scary the most? I go have a mammo. Okay. They have to tell me right away. Okay if they see anything. So I sit there in that room after they do it and I wait and I wait. If they call me back for an ultrasound then my heart starts going. Because that's the second look. When I go in I do the mammo and then they ask you to sit outside and wait. So you sit there and wait and wait. And you get a little nervous thinking oh god. Especially when it takes a little while. If they come out and say you are OK then your face lights right up. If they come out and say you need an ultrasound then you have something to worry about. Because that's what they did to me.

**Inability to Control Cancer.** A cutting point described by participants in the current study was Stage IV-Accepting Cannot Control Cancer. Breast cancer survivors look for an answer why breast cancer occurred. Taylor (1983) introduced the theory of cognitive adaptation from data analyzed from 78 breast cancer survivors using interviews and questionnaires. Taylor (1983) was not clear with what method she used to analyze the qualitative data. The theory of cognitive adaptation has three themes: the search for meaning, gaining a sense of mastery and self enhancement. Taylor (1985) reported when breast cancer survivors attempt to gain a sense of mastery, they use causal attributions to understand, predict and control their environment in response to futilely find the cause of their cancer. In the current study, this stage was hallmarked when the breast cancer survivor acknowledged acceptance that she could not control the diagnosis of cancer and changed her focus to seeking attainment and maintenance of emotional order. One participant talked about this realization:

That's when I kind of realized this illness isn't really any illness. It's really doesn't pick and choose. I mean it does pick and choose how it affects and maybe it is a roll of the dice.

The discovery of Stage IV-Accepting Cannot Control Cancer is consistent with findings in the literature by Arman & Rehnsfelt (2003), Taylor (1983) and Wallston et al. (1987) who reported a turning point that was marked with the realization that although the breast cancer survivor could not control the diagnosis but could control how they react to the diagnosis.

### **Creating Emotional Order**

In the current study, the participants created emotional control in response to recognizing that they could not control cancer. The participants in this study created

personal emotional order by compartmentalizing, controlling actions, social comparison, benefit finding and participating in planned helpfulness. These methods of creating emotional order are coping mechanisms that was found in the current literature.

**Compartmentalizing.** Compartmentalizing is a coping mechanism that participants used in this study. In response to reminders of breast cancer, participants chose not to think about the threat and placed these thoughts into the “back of their heads”. Several participants discussed compartmentalizing to avoid negative feelings to create emotional control. Ruiter, Verplanken, Kok, and Werrij (2003) reported that threatening information contributes and may act as a threat to emotional control initiating coping mechanisms or compartmentalizing.

Tacon, Caldera, and Bell (2001) studied attachment style, emotional control in women who had been diagnosed with breast cancer ( $n= 52$ ) within one to fifteen years prior to the study. Tacon et al. (2001) explored links between classic attributes of Type C avoidance attachment styles specifically suppression of negative emotions and breast cancer. Tacon et al.’s (2001) findings supported their hypothesis that women who have been diagnosed with breast cancer would have higher avoidance attachment scores thus having higher emotional control than women who have not had breast cancer. Tacon et al., (2001) findings are consistent with the process reported in this study of compartmentalizing negative feelings about breast cancer to create emotional control in Stage V.

**Social Comparison.** Social comparison was introduced by Festinger (1954) as the process individual uses to self-evaluate and clarify reactions to emotions in response to threat. Social comparison can be either upward or downward. Upward social comparison is when an individual compares themselves with another individual who has a problem similar to theirs and is perceived to be adjusting well to the situation (Festinger, 1954; Taylor & Lobel, 1989; Wood, Taylor & Lichtman, 1985). This has been found to be a coping mechanism used by breast cancer survivors for self enhancement, to gain hope and to seek resources to improve themselves (Wood, Taylor, & Lichtman, 1985).

Downward social comparison is when an individual compares themselves to someone they perceive is less fortunate (Festinger, 1954; Taylor & Lobel, 1989; Wood, Taylor & Lichtman, 1985). This is a coping mechanism individuals use to preserve self-esteem, minimize their own situation and to decrease the sense of victimization. One participant's narrative indicated downward social comparison:

See people who have chemo go through more hell. I mean I know I had a lot of surgeries and stuff but my heart goes out to the people who have to take the chemo. Because I am experiencing it through my step-daughter. And she went through needles. The chemo made her deathly sick. I would clean throw up off the floor and in the bed. She tried to make it. She was on a feeding pump. Those are the people I pity. I mean surgeries you get better. They had to deal with that for probably, T. dealt with that for a whole year. And it was hell. It really was.

Frequently in the literature, downward social comparison was found to be a coping mechanism used in response to the threat of breast cancer. (Legg, Occhipinti, Ferguson, Dunn, & Chambers, 2011; Stanton, Danoff-Berg, Cameron, Snider, & Kirk, 1999; Taylor, 1983; Taylor & Lobel, 1989; Wilkins & Woodgate, 2011; Wood, Taylor, &

Lichtman, 1985). Social comparison is found in the literature to aid positive adaptation in breast cancer (Legg, Occhipinti, Ferguson, Dunn, & Chambers, 2011; Taylor, 1983; Stanton, Danoff-Berg, Cameron, Snider, & Kirk, 1999; Wilkins & Woodgate, 2011; Wood et al., 1985). Legg et al. (2011) found exposure to other breast cancer survivors allowed for upward comparison thus encouraging optimism and hope. This was consistent with this study's findings as highlighted by a participant's recollection of going to a support group:

It was very helpful because there were so many women there that told their stories. Actually, I felt good because my tumor was discovered so early that in comparison to many of the others, I felt that I had a better prognosis.

Social comparison was a frequently used coping mechanism to create emotional order in the participants of this study. The participants in this study used upward and downward social comparison to create emotional order.

## **Modifiers**

**Information.** Information played a part in modifying the process of negotiating emotional control. Information in this study was shown to modify emotional order by causing fear or by allowing the participants to become knowledgeable about their disease. Information also created comfort and provided positive feelings in several participants in this study. Information was also sought by the participants in this study as a means to create emotional order. Many of the participants spoke of actions they had researched and were applying to their lifestyles to decrease their risk of cancer recurrence. Fear also was elicited by information, especially in modern times where the participants have easy access and use the Internet as a means of information. Feelings of fear related to Internet information were shared by this participant:

The fear was overridden for those couple days when I did research and I had no idea what I was looking at on the Internet. It is one thing Karen told me last week, “Do not, do not, do not, do any research.” You don’t know what you’re reading. What I read, and I remember the words and I don’t know if it was in relation to the hormone-negative HER, prognosis poor. That’s all I could see was the prognosis was poor and I sat on my front porch and cried for a few hours. Luckily I was seeing Ray the next day and we went through and processed it all and I found my puppy and went on from there.

Informational needs of long-term survivors were also found in the literature.

Garcia and McQueen (2005) reported that long-term breast cancer survivors continue to have informational needs that are often unmet by healthcare providers. As result of unmet needs, breast cancer survivors seek information from alternative sources including support groups, books and the Internet. Informational needs were found to be as prevalent in the post treatment stage as they were in the treatment decision stages (Rutten, Arora, Bakos, Aziz, & Rowland, 2005). Additionally, in this study breast cancer survivors felt the need for continuing education in order to assist other breast cancer survivors as highlighted by this participant’s narrative:

Yes it has been and the people that we have helped through it. It has been amazing. I found that through breast cancer there is a lot of information for breast cancer survivors. But there is nothing for other cancer survivors. Very minimal. So I welcomed them all in. Share the wealth. They go through the same things we do. Whether its colon or it is lung, pancreatic.

**Interpersonal Influences:** Interpersonal influences affected emotional order by modifying in positive and negative ways. The participants in the current study referenced healthcare providers frequently. The healthcare providers they referenced were: nurses, medical providers, radiology technicians, sonographers and office staff. Interactions among the breast cancer survivors were an important aspect of their care from recognition of an abnormality into extended survivorship. These findings show the

contribution of healthcare providers as credible authorities and also sheds light on the perception that breast cancer survivors have of the care they receive and in what manner or environment they receive it in. The lesson revealed in the current study emphasizes the power of effective communication between healthcare providers and the breast cancer survivors. Furthermore, in this study, all members of the healthcare team impacted care. The team included secretarial staff who were often the first person with whom the survivors had contact and also technician staff who performed diagnostic exams on the survivors. The power of communication with all of the healthcare team was found to be profound and either aided or hindered emotional order. An example of negative communication was shared by this participant regarding how she was made to feel by the radiologist and technicians:

Dr. C was horrible and I sobbed, I'm not a sober. I mean if somebody dies that's close to me. I'll cry, but he said to me probably at least 10 times, "This will be a piece of cake, piece of cake, piece of cake." I had read Susan Love's book and I had read all these different books over the course of like five or six days and I asked him if I needed the tattooing. I just didn't know if I wanted that. It was trivial, but it was my one area of control and I said do I really need the tattoos? He said no, not really. I said okay and I went in there whatever to get formed up you know how you get melted into your form for radiation. I said now we're just going to have to do the markers and I went: What are you talking about? The markers? Dr. C said I didn't them. The tech responded... Well he really doesn't really know what he's doing. I said what and meanwhile I'm on the table I have the machine going. I said WHAT and I started flipping out and I said...and it wasn't so much I was flipping out about having to have markers. It was I was flipping out about the fact that somebody was saying that my radiologist, oncologist didn't know what he was doing and that he had lied to me. What did that bode for the rest of the rest of the treatment?

Participants in this study also expressed positive interactions with members of the health care team. In another example given by a participant, her experience was positive and created feelings of confidence:



The compassion between Dr. S and Dr. S. The time that they took. We all know how busy lives are, especially for doctors. They took the time to make sure that my needs were met and put their schedules for that moment in time on hold for me. I will always be thankful for that. They were professional at the same time caring to a point where you didn't feel like you were being treated as a patient, more like a friend. And I never met Dr. S before I went to see him. I was the first time I met him. D (husband) came with me and we sat in his office and he has a waiting room of full of people and they didn't ever matter at that point. I mattered. They didn't matter at that point because I was sitting in his office. He explained everything in simple, simple terms so D and I could both understand to the point that every single question was answered. He would not let us leave his office until there were no more questions. And there were people waiting an hour and a half after their appointments to see him because he sat there. The only thing that mattered at that moment was my cancer. It was very cool. It was amazing. I could have gone and had second opinions but I didn't feel like I had to. I was treated so well. They put so much into this that I didn't need to go get a second opinion. The whole team was wonderful.

The modifying nature of interpersonal interactions with physicians and nurses and breast cancer survivors was found in the literature (Collie et al., 2005; Hilen, De Haes, & Smets, 2011; Tovey & Broom, 2007 ). Collie et al. (2005) reported that problematic interactions with healthcare providers decreased self- efficacy and satisfaction. There appears to be a dearth of information on the impact that members of the healthcare team including secretarial, ancillary staff and technicians make in the breast cancer treatment experience. Several of the participants, in the current study, expressed difficulties with these members of the health care team and there was a gap in the literature found pertaining to this population who has contact with the population of interest. Thus this impact of non-licensed medical providers is a significant finding of this study.

### **Contribution of Findings to Current Knowledge**

Besides the Sherman et al. (2012) study, no other studies were found that examined the process of survivorship in women who completed treatment for breast cancer. This study affords a glimpse into the experience of survivorship from the

perspective of the woman who has completed treatment for breast cancer as to how they survive emotionally from the detection of an abnormality into extended survivorship. This study contributes to the literature as there is a lack of research done on the process of extended survivorship.

Many studies have examined fragments of the process of survivorship. The current study's findings propose a holistic process of survivorship that is affected by time and is perpetual. This information may help healthcare providers understand the immediacy that breast cancer survivors experience during certain cutting points in the disease trajectory and potentially the results of this study can augment and improve care for breast cancer survivors. Specifically important to the participants in this study was the cutting point that was found to occur immediately after the completion of treatment or transitional survivorship. This study identified transitional survivorship within the population of breast cancer survivors.

This study suggests that women who have completed treatment for breast cancer negotiate emotional control to preserve emotional health. Emotional health was important to the participants in this study. The current study informs of the need for ongoing emotional care into extended survivorship, which healthcare providers and nurses can directly impact. Moreover, this study highlights the idea that emotional duress can impact breast cancer survivors' overall well-being. The findings of this study prompt healthcare providers to ask about and assess for emotional disequilibrium due to the diagnosis of breast cancer. Last, the findings in this study present the concept that the fear of recurrence can last perpetually and be an issue that is important to the survivor until the end of their lives.

Healthcare providers themselves were found to be interpersonal influences that strongly influenced the process of negotiating emotional order. Specifically, health care providers are in an optimal position to assist breast cancer survivors emotionally and physically. It is important that healthcare providers acknowledge the devastating emotional as well as physical effects of breast cancer. Information also acted as a modifier and health care providers often are the credible authorities that influence and create a gateway for breast cancer survivors to seek and obtain information.

A principal contribution of the findings from this study is an insight into how breast cancer survivors negotiate control to create emotional order when faced with the threat of breast cancer. The foundational assumption of this study was that breast cancer survivors endure a multifaceted, complex process until the end of their lives. It was also assumed with the lack of empirical literature to draw from on this process that some properties of this process may be concealed. The current literature did not provide holistic accounts or descriptions of breast cancer survivors' perspectives of the survivorship process.

This study contributes to the literature as it directly challenges Mullan's (1985) model of cancer survivorship. Overall the survivors were motivated to negotiate emotional control to protect them emotionally. What is most significant is the model that emerged from the data describing this process being much more complex than the model proposed by Mullan (1985) describing cancer survivorship. The linear, yet potentially cyclical model that emerged from this process challenges the prepackaged model of cancer survivorship that is found in major cancer support resources worldwide. The theory that emerged of negotiating control asserts that the seasons of survivorship model

proposed by Mullan (1985) may not be one size fits all for all cancer types and that the breast cancer survivorship process is complex and that breast cancer survivors have tailored needs.

This study redefined the seasons of survivorship for the population of breast cancer survivors. By highlighting the periods of intense emotional distress during the acute, transitional and extended periods this study allows health care providers to be aware and proactive in the care they give to breast cancer survivors during these times in the disease trajectory and beyond. Additionally, understanding the grounded theory of negotiating emotional order allows healthcare providers to understand breast cancer survivors' process of decision making when faced with the threat of breast cancer whether when initially diagnosed or when confronted with recurrence.

The grounded theory of negotiating control may allow the perspective from women who have completed treatment for breast cancer to contribute to the current literature. Participants described a complex, multidimensional process that they use to navigate decision making to attain emotional order in their lives. Participant's narratives were examined and analyzed to explore the judgments made about the fear caused by the threat of breast cancer.

### **Summary**

In this section, the findings of the study, the grounded theory of negotiating emotional control was discussed. Modifiers were found to be part of the factors that the breast cancer survivors took into consideration when they made decisions and or acted in response to the threat of breast cancer, specifically interpersonal influences. Extant

literature and contributions to the literature were examined and debated. Some of the elements of the social comparison theory and the theory of cognitive adaptation were found to be similar to the process of negotiating emotional control. Significant contributions to both modern and extant literature were identified as confirmation that transitional survivorship is part of the survivorship process, redefining of the seasons of survivorship for breast cancer survivors, identification that the fear of recurrence is perpetual, identification of healthcare providers as a strong interpersonal influence. Furthermore this study may stimulate future research on the roles and impact of non-licensed healthcare providers on emotional control within the care of breast cancer survivors.

## ***CHAPTER VII.***

### **Conclusion**

Grounded theory derives from real world life experiences. The women who participated in this study offered contextual descriptions of how they negotiate emotional control in order to achieve emotional well-being. Breast cancer survivorship has neither extensively nor holistically explored previously in the literature. The results of this study suggest that the process of survivorship is impacted by psychological aspects of the diagnosis, specifically the threat of recurrence once treatment is completed.

The grounded theory that emerged is significant as it adds the theory base for designing future intervention studies to address psychological concerns of breast cancer survivors. Furthermore, this study contributes to the emerging knowledge base of this population and potentially will stimulate further research. Most importantly this study has allowed breast cancer survivors to have a voice and express their concerns.

### **Implications for Nursing Practice**

Nursing is a holistic art that encompasses the care of the body and the mind. Nurses encounter breast cancer survivors frequently in clinical practice from the bedside, office settings to advanced practice in primary care. The numbers of women who are breast cancer survivors are growing due to increased screening and improved survival rates. Additionally, there is an increased role of advanced practice nurses in the health care arena that allows the opportunity for nurses to improve the health and psychological outcomes of this population greatly by understanding the Theory of Negotiating Emotional Order.

The Theory of Negotiating Emotional Order allows an aperture into the survivorship process breast cancer survivors endure. In this study, women who completed initial treatment for breast cancer had the main concern of negotiating emotional control. This struggle was evident from the time that an abnormality was found until the end of the survivor's life. Knowing that the survivorship process has a perpetual quality, as evident in this study, gives nurses the opportunity to develop mechanisms to assist breast cancer survivors as they negotiate emotional control over the lifespan. Importantly, nurses should consider women with the diagnosis of breast cancer to be at risk for psychological duress from the detection of an abnormality for the rest of the breast cancer survivor's life.

Nurses themselves can act as a powerful interpersonal modifier through their interaction with actions and words with breast cancer survivors. Disseminating the discovery of the Theory of Negotiating Emotional Order through educational programs may allow for improved patient satisfaction and improved health/psychological outcomes for this growing population.

One of the most significant findings in the initial literature review was un-met needs, specifically information. Information was found in this study to be a modifier well into extended survivorship. Nurses routinely do much of the patient education in the healthcare setting. The understanding that breast cancer survivors desire information well after diagnosis may allow for nurses to be culturally sensitive to this population and allow them to provide breast cancer survivors with information about the dynamic process they are undergoing.

In this study, there was often a loss of emotional control during screening blood work and healthcare visits. As nurses work closely with patients this may be an opportunity to inquire about psychological wellness when the breast cancer survivor seeks health care. Potentially, questions used in the interview guide of this study could serve as a source of health history assessment tailored for this population. This information may assist nurses in identifying un-met needs or informational deficits and allow for additional psychological screening and/or referrals. Psychological well-being is difficult to quantitate. If nurses ignore the psychological aspect of wellness in breast cancer survivors, it may interfere with the nurse's ability to assist the breast cancer survivor and restrict the woman's ability to attain overall health.

### **Strengths of the Study**

The first strength of this study was that the findings are grounded in the narratives expressed by women who had completed treatment for breast cancer. This perspective had not been extensively studied in the past and exploration of this growing population is recommended and a national initiative. With the numbers of survivors growing and having a significant presence in the current health care arena, this population's concerns and needs are merited to be obtained and understood. Grounded theory methodology allows for theories to evolve in real time, with the ability to create tools which are current and are useful. Thus, this study has the potential to benchmark development of tools that can predict psychological distress, potentially leading to early intervention and improved patient outcomes.



An important strength of the study was the range of the years of survivorship that was reported. The participants ranged from three months to twenty-four years from the completion of adjuvant treatment of breast cancer. This allowed for a wide representation of survivorship phenomenon over time. Additionally, this sample included women who had had recurrence and metastatic disease. This offered a realistic view of the population of interest.

### **Limitations of the Study**

This study was based on in-depth interviews of twelve participants. There are several limitations in this study. First, the researcher attempted to recruit a variety of participants from diverse social and demographic backgrounds through flyers posted in public places. Despite this, the entire sample was Caucasian, the majority of the sample was married or partnered, all of the participants held high school education or equivalency and the majority of the sample had three or more years of college education. Economic and insurance status information was not included in the demographic data. Expanding the demographic sample may have further informed the study and would have allowed further modifiability of the theory to explore additional relationships between these variables and the process of survivorship.

Another limitation of this study was the inexperience of the researcher. Employing a grounded theory study is a substantial endeavor and requires a multiplicity of skill sets that is learned while applying the research method. As a novice researcher, interviewing skills improved as the study progressed and focused on emerging core

categories. Furthermore, access to experienced grounded theorist mentors was sought as the researcher acknowledged this limitation.

Lastly, grounded theory analyses are population specific. This study represents the primary step in theory development. The aim of grounded theory construction is to hone and develop the theory further in the attempt to produce formal theory. Further testing the applicability of this theory to additional participants and populations is warranted. This would be useful to ascertain whether the process of negotiating emotional order is used by others who have experienced a life threatening illness. While limitations did exist, this study has the potential to stimulate further research on the process of negotiating order in women who have completed treatment for breast cancer.

### **Implications for Knowledge Generation and Practice**

Identification of the process used by breast cancer survivors to negotiate emotional order may be helpful for health care providers who care for, educate and design nursing interventions for this population. Understanding the decision making process used by women who have completed treatment for breast cancer may assist health care providers to facilitate positive health outcomes and achieve more holistic and individualized care for breast cancer survivors.

This study reinforces the disparity between the currently accepted stages of survivorship and the actual process that breast cancer survivors endure. This study showcased the fact that the accepted seasons of survivorship described by Mullan (1985) may not be the best fit to describe the process that breast cancer survivors endure once they complete initial treatment. Additionally, this study was an attempt to begin to bridge

the gap in the literature and explore the process of survivorship from the perspective of women who have completed treatment for breast cancer in order to gain an augmented understanding of this population of interest.

### **Recommendations**

Based on the findings of this study, further research is recommended in regards to negotiating emotional order in women who have completed treatment for breast cancer. Replication of this study is recommended to further expand and test applicability to additional populations. Furthermore, the theory could be refined and expanded from data collected from additional participants' interviews. In subsequent analyses, the recruitment strategies could be vigilant to include variation of racial and ethnic participants to expand this theory's overall generalizability.

Identification of the process of negotiating emotional control may be useful to health care providers who care for this population in primary care and acute settings as it explains how physical reminders may trigger feelings of loss of life order that will prompt breast cancer survivors to seek care. Furthermore, this study provides insight on the immediacy of seeking care for an abnormality as this often causes emotional distress in regards to the fear of recurrence that appears to be perpetual in this population.

Consideration of the emotional impact of breast cancer should be considered throughout the lifespan of the survivor in all settings where healthcare providers and patients collectively interact. In addition, health care providers need to acknowledge that although the breast cancer survivor may appear to physically be doing well, she may be struggling emotionally with the aftermath of the diagnosis. Communication and

assessment of psychological wellbeing is an important aspect of this population healthcare. The resulting collaborative relationship of the healthcare provider and the breast cancer survivor may result in improved overall physical and emotional outcomes.

### **Summary**

Through the use of grounded theory methodology, this study allowed a modern day observation of the process of survivorship as experienced by women who have completed initial treatment for breast cancer. A practical theory of negotiating emotional order has been revealed in this study. As stated in the introduction of this paper, “Apprehension, uncertainty, waiting, expectation, fear of surprise, do a patient more harm than any exertion” (p.25, Nightingale, 1859/2003). The findings of this study prove this nursing icon’s hypothesis is true. In this study of the grounded theory of negotiating emotional control, apprehension, uncertainty, waiting expectation and fear of surprise all generate emotional duress in breast cancer survivors that participated in this study.

This study contributed to the literature in several ways and the findings may help healthcare providers who care for breast cancer survivors understand the depth and perpetual emotional impact that breast cancer survivors endure. This study will potentially serve as path for future research and aid in the understanding of the psychological impact that breast cancer has upon survivors.

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## Appendix A Review of Literature

Review of Literature Definitions of Survivorship

Studies	Focus	Subjects	Population	Age	Method	Findings
NCCS (1983)	Cancer Survivorship				Definition	Cancer survivorship begins at diagnosis and ends with death
Mullan (1983)	Cancer Survivorship	N=1	Male Lung Cancer Caucasian	32	Narrative Interviews	Phases of Cancer Survivorship: <i>Acute, Extended, Permanent</i>
Miller et al. (2008)	Cancer Survivorship				Assertion	Expanded Mullan's (1983) Phases of cancer by including phases Added transitional survivorship; expanded extended survivorship: maintained remission, cancer free, living with cancer; expanded permanent survivorship: cancer free and free of cancer, longterm problems secondary to cancer, second cancers, secondary cancer
Pelusi (1997)	Breast Cancer Survivorship Phenomenon	N=8	Women who had Breast Cancer as a diagnosis and had completed treatment: 2-13y, range 7.6 years 6 Caucasian, 1 Latina, 1 African American	34-70	Phenomenology	Breast cancer survivorship begins at diagnosis. Essential structure of breast cancer identified.
Bulki et al. (2009)	Breast Cancer Survivorship	N=18	Latina breast cancer survivors Time since ended treatment not reported	33-67	Focus groups divided by Mullan (1983) Phases: Acute, extended and long-term survivorship	Differed from Mullan as used long-term survivorship instead of permanent survivorship. Identified 3 experiences: perceptions of psychological well-being, need for social support, impact of well-being, treatment effects and attitude development. Psychological well-being and social support in all phases. Impact of well-being only present in acute phase. Impact of well-being and new attitude development found in extended and long-term phases.
Galvan, Bulki & Garcés (2009)	Breast Cancer Survivorship	N=22	Latina Breast Cancer survivors	33-47	Focus groups divided by Mullan (1983) Phases: Acute, extended and long-term survivorship	Differed from Mullan as used long-term survivorship instead of permanent survivorship. Identified three phases diagnosis, treatment & after-treatment

Review of Literature Describing Unmet Needs of Cancer Patients

Studies	Focus	Subjects	Population	Age	Method	Findings
Allen, Savadatti & Levi (2009)	Transition from patient to survivor	N=47	Breast cancer, completed treatment in prior 12 months. 81% Caucasian 15% African American	Range 35-86 Mean 57	Focus Groups	The period of time when women who have been treated for breast cancer transition to life without treatment presents numerous emotional and physical challenges. Positive life changes, fear of recurrence, emotional distress, difficulty returning to normal, losses associated with the end of treatment. For younger women impact of treatment on fertility was acute.
Aranda et al (2003)	QOL and unmet needs	N=105	Breast cancer survivors with metastatic cancer or progression of disease were inclusion criteria. Race not reported. In treatment, diagnosed within 12 mths	Range 34-85 Median 57	Questionnaires Life Q-C30 Supportive Care Needs Survey (SCNS)	Between one quarter and a third of the women reported difficulties with their physical, role and social functioning, and a little over a quarter of the women reported poor global health status. Fatigue was a problem for most women. The highest unmet needs were in the psychological and health information domains. Almost no differences in unmet needs were detected when comparing different demographic and disease characteristics of women.
Armes et al. (2009)	Cancer Survivors Un-met needs	N=1,425	Cancer survivors 57% Breast Cancer 97% Caucasian	Mean 61y	Prospective longitudinal study at the end of treatment and 6 months later backward stepwise logistic regression Questionnaires Supportive Care Needs Survey (SCNS), Health Concerns Questionnaire (HCQ), Hospital Anxiety and Depression Scale (HADS), The 20-item Positive Affect and Negative Affect Schedule (PANAS)	30% reported more than five unmet needs at baseline, and for 60% of these patients, the situation did not improve. At both assessments, the most frequently endorsed unmet needs were psychological needs and fear of recurrence. Logistic regression revealed several statistically significant predictors of unmet need, including receipt of hormone treatment, negative affect, and experiencing an unrelated significant event between assessments.



Studies	Focus	Subjects	Population	Age	Method	Findings
Besty et al. (2008)	Psychological needs of breast cancer survivors	N=34	7 focus groups divided into 3 categories; 19 Patients diagnosed with breast cancer within past 12 months, oncology nurses, volunteers that work with cancer survivors. Race not reported.	Mean age of breast cancer survivors 53.5 years Time since dx Range 2-25-18 years Mean 7.73	Focus groups	five major themes were extracted: Coping with Side-Effects; Self-Concept Change: physical, personal and social aspects (role changes); Stress and Adjustment Reactions: related to diagnosis, treatment and treatment completion (loneliness); Managing Others (game face); and Survival
Beliz & Blank (2006)	Posttraumatic Growth	N=224	Breast Cancer Survivors Randomly selected. 1 year out from treatment and no more than 4 years post-treatment African American N=8 Latina N= 9	Range 32-86 Mean 60	Survey LOT-R to measure dispositional optimism HOPE scale, a 12-item self-report scale Brief COPE scale PTGI	Women who rated the time of diagnosis as a time of increased emotional intensity had increased post diagnosis growth. Hope and optimism did not account for variance with post diagnosis growth. Current age and employment did account for increased post traumatic growth.
Bower et al. (2005)	Positive meaning and vulnerability	N=763	Breast cancer survivors 83.79% Caucasian 8.79% African American	Range 30-87 Mean 55.6	Questionnaires longitudinal at 1-5 year and 3-10 years post diagnosis Used tool developed for this study based on ROL, focus groups to measure positive meaning and vulnerability.	Positive meaning and vulnerability were present at both assessments. Vulnerability associated with negative affect. Meaning associated with positive affect. 40% reported fear of recurrence up to 10 years post diagnosis
Bowman et al. (2010)	PCP Involvement in survivor care Un-met needs	N=215	Cancer Survivors 50% Breast Cancer 74% Caucasian	Mean age 76	Questionnaire from a larger study. Secondary analysis on data from large study Dependent Variables: Discuss cancer history with PCP Independent Variables: Demographic, cancer characteristics, Survivor-PCP, health, psychosocial well-being	Patients perceived the PCP as being involved in follow up care. 2/3 indicated they had discussed the cancer history with PCP, these discussions were initiated by PCP and resulted in additional tests. PCP initiated discussions happened most frequently with Breast cancer survivors.

Studies	Focus	Subjects	Population	Age	Method	Findings
Burke et al. (2011)	Meaning of survivorship Support	N= 63 total N=31 Filipino Breast cancer survivors	Staff N=6 Support Group Participants N=21 Breast cancer survivors, N=6 male family members Women No Support Group N=27 Women Left Support Group N=3 Length of time since dx not reported.	Not reported	Ethnography	Themes found: cancer is one of many trials that women have had to go through; survivorship not about self but about family; Survivorship like a rebirth a second chance. Dimensions of caregiving: offering stories bolstered their own spirits, women denied having a caregiver assist them; Family support dynamics; survivors have dual role of caregiver throughout dx and treatment; additional financial responsibilities in the Philippines; Spiritual and religious support
Cappiello et al. (2007)	Information and support	N=20	Breast cancer survivors. Time from completion of treatment 7-60 months, mean within 2 years	Range 33-80 Mean 52	8 in-person and 12 telephone interviews, semi structured focused on the presence of common physical and emotional symptoms and perceptions about these experiences with a specific focus on the 3-, 6-, and 12-month time points after completion of therapy.	Themes: Physical distress: fatigue, difficulty remembering, sleep difficulties, hot flashes; Fear of recurrence lasted throughout all the timeframes; Informational needs 43% reported they did not receive any information on transition; struggle to return to normalcy; end of treatment was seen as a challenge
Cheung et al. (2009)	Patient & Physician Expectations of survivorship care Communication	N= 913 total N=333 survivors N= 255 PCP N=123 Oncologists	Cancer survivors 30% breast cancer 94% Caucasian	Survivors age range 16 to 91 Mean 57 PCP/ONC Age range 31-79 Mean 50	2 separate questionnaires developed for patients and the providers	Patients and PCPs reported they anticipated significantly more oncologist involvement. PCPs reported they should contribute a much greater part to this aspect of care. PCPs and oncologists reported discordances in perceptions of their own roles for primary cancer follow-up, cancer screening, and general preventive health. Both PCPs and oncologists indicated they should carry substantial responsibility for follow up care.
Clemmons et al. (2008)	Patterns of long-term survival	N=19	Cervical Cancer Caucasian Rx for cervical cancer 7-28 prior to interview	Range 29-64	Semi-structured Interviews	Similarities: time around diagnosis; view of healthcare providers either in a positive or negative way; coping strategies used to deal with diagnosis, treatment and complications

Studies	Focus	Subjects	Population	Age	Method	Findings
Coggin & Shaw-Perry (2006)	Breast Cancer Survivors Expressed Needs Un-met needs	N=62	African American Breast cancer survivors Timeframe since Dx and Rx not reported	30-80 Mean 53	Delphi Technique for deriving cultural consensus Questionnaire developed by authors	The five theme areas were: (1) physical needs (2) social needs (3) psychological needs (4) spiritual needs, and (5) financial needs.
Constanza et al. (2007)	Adjustment to life after treatment and QOL	N=113	Breast cancer survivors Measured during treatment, at 3 weeks after Rx and 3 months after Rx. Race not reported.	Range 32-89 Mean 55	Questionnaire The Center for Epidemiological Studies Depression Scale (CES-D) Primary Care Evaluation of Mental Disorders Patient Health Questionnaire (PRIME-MD PHQ) Impact of Events Scale (IES) Memorial Symptom Assessment Scale (MSAS), The Medical Outcomes Study Short Form 36 Version 2.0 (SF-36v2)	Fear of recurrence prevalent. Post-treatment distress present at baseline 19.3%, 3 wk. 22% and 3 mth. 17.4% Cancer specific distress prevalent through all 3 timeframes. QOL increased as time progressed. Getting back to normal and leaving treatment caused increased stress. Age, education & history of depression predicted depression in this population
Doumit et al. (2010)	Coping Psychological	N=10	Lebanese breast cancer 4 months to 9 years after diagnosis	Range 36-63 Mean 51.3	Phenomenological	Factors promoting Coping: cancer something from God, cancer similar to other diseases like DM, Sought to share experience with other survivors, positive support from work, family and spouse. Hindering Coping: changed body image: loss of hair; Fear of recurrence, being pitied. Cancer a continuous battle
Gallia & Pines (2009)	Identity and spirituality	N= 11	Breast cancer African American 1-10 years since diagnosis	Range 40-85	Narratives	Redemptive imagery, Agency, call to be of service to others, idealized self-images and role modeling and religion
Gorman et al. (2009)	Breast feeding	N=11	Breast cancer survivors. Diagnosed within 4 years.	All were <40 at time of diagnosis	Interviews	Themes that emerged 1) Cautiously hopeful, 2) Exhausting to rely on one breast, 3) Motivated despite challenges, 4) Support and lack of support, and 5) Encouraging to others.
Gorman et al. (2011)	Young breast cancer survivors	N=20	Breast Cancer 7 Caucasian 3 Latina Were diagnosed 1-13 prior to study	Range 26-38	Telephone interviews	The main themes were (1) "I was young, I wanted to do everything possible to move forward with my life and not to have the cancer come back"; (2) "Fertility concerns are different for every woman"; (3) "My oncologist...was great a huge part of my survivorship"; and (4) "They didn't tell me about my options, and I didn't think about fertility until it was too late."

Studies	Focus	Subjects	Population	Age	Method	Findings
Jefford et al. (2008)	Survivorship issues Un-met needs	N=22 survivors 7 men, 15 women Had 4 focus groups: survivors, doctors, nurses and allied health professionals. Numbers not reported on the later 3.	Cancer Survivors N=7 Breast cancer	<30 to >60 Majority N=13 were between 30-60	Focus groups at end of treatment and 12 months later	Survivors reported: difficulties returning to normal life, losing support, structure and routine of treatment, needed another person who has gone through similar situation, had difficulty with family friends thinking they no longer needed support, self-identity changes, Fear of recurrence, uncertainty of future, depression, loneliness, reported informational needs after treatment ends, feeling abandoned or cast off by healthcare system
Kantsiper et al. (2009)	Transition to breast cancer survivorship Health-care	N=21 Survivors N= 15 PCPs N=Oncologist	Breast cancer 16 Caucasian. Time since diagnosis 12<5 years, 3 > 10 years	Age not reported	Focus groups	Survivors derive reassurance from specialty care and surveillance, felt PCPs not prepared to handle their cancer specific needs nor wanted to overstep their position in survivorship care. Reported few oncologists or PCPs addressed the physical, psychological and social aspects of the cancer experience
Lebel, Roseberger & Devins (2007)	Stress Psychological	N= 72	Breast cancer survivors newly diagnosed	Range 37-88 Mean 61.7	adapted version of the original Ways of Coping Questionnaire	3, 7, 11, and 15 months, and at 6 years after diagnosis. Stressors included fear of the future; Physical limitations; pain; and problems with family or friends due to cancer. Fear of recurrence ranked on top of stressors, peaked 15 mths to 6 years then stabilized
Loerzel et al. (2008)	QOL in first year of survivorship	N=30	Completed treatment for breast cancer 82% Caucasian	Range 65-83 Mean 72	Longitudinal repeated measure secondary analysis of BCEI study Breast Cancer Treatment and Quality of Life in Aging Breast Cancer Survivors (QOL-ABCS) Sociodemographic Data Tool Explored QOL: physical, psychological, social and spiritual	Physical and psychological well-being declined from baseline to time 2 and time 3. Social well-being improved at time 2 but declined at time 3. Spiritual well-being declined at time 2, then improved at time 3. Overall QOL good at baseline then declined over time.
Lobb et al. (2009)	Unmet needs at completion of treatment	N=66	Blood Cancers 6 weeks to 12months after the completion of treatment. Race not reported	Range 18-80 Mean 34	Questionnaires Mailed The Cancer Survivors Unmet Needs measure (CaSUN)	The most frequently endorsed patient needs related to Care co-ordination and help to manage the fear of recurrence. The most frequently endorsed unmet needs included managing the fear of recurrence, the need for a case-manager and the need for Communication between treating doctors. Predictors of unmet needs included younger patients ( $p = 0.01$ ), marital status ( $p = 0.03$ ) and employment ( $p = 0.03$ ). Almost two-thirds of patients (59%) reported they would have found it helpful to talk with a health care professional about their experience of diagnosis and treatment at the completion of treatment and endorsed significantly more need in the Areas of Quality of Life ( $p = 0.03$ ) and Emotional and Relationships ( $p = 0.04$ ).



Studies	Focus	Subjects	Population	Age	Method	Findings
Mellinger et al. (2006)	Family communication Mental Health psychological	N=234	Breast Cancer Survivors. Completed Rx at least 3 mths prior to enrollment. 91% Caucasian 7% African American	Mean age 57	Mail Survey Family Avoidance of Communication about Cancer Scale developed by authors Medical Outcomes Study Short Form 36	Family avoidance and mental health negatively correlated in both bivariate and multivariate. Family was not defined in the questionnaire. Stage of disease not collected.
Mao et al. (2009)	Survivorship care by PCP Communication	N=286	Breast Cancer 84% Caucasian Completed treatment 1 month before enrollment	Mean age 61	Cross-sectional Survey Developed a seven-item Primary Care Delivery of Survivorship Care Scale (PCDSCS)	The areas of PCP-related care most strongly endorsed were general care (78%), psychosocial support (73%), and health promotion (73%). Fewer BCSs perceived their PCPs as knowledgeable about cancer follow-up (30%), late effects of cancer therapies (39%), or treating symptoms related to cancer or cancer Therapies (41%). Only 28% felt that their PCPs and oncologists communicated well. In a multivariate regression analysis, nonwhite race and level of trust in the PCP were significantly associated with Higher perceived level of PCP-related survivorship care ( $P < .001$ for both).
McDowell et al. (2010)	Unmet needs	N=396	Blood or tumor cancer 78% had completed treatment	Range 22-89 Mean 59.3	Questionnaires SCNS Once then six months later	
Rosedale (2009)	Loneliness Psychological	N=13	Breast cancer survivors; 1-18 yrs. after completion of treatment. 10 Caucasian, 3 African American	Range 33-74	Phenomenology	Ongoing symptom experience of women and isolation. Loneliness reported by all participants, some women are more vulnerable to heightened psychological distress
Sadler-Gerhardt (2010)	Change and Meaning	N=8	Breast cancer survivors who completed treatment within 3 years 6 Caucasian 2 African American	Range 28-80	Phenomenological and case studies	Women in childbearing age, infertility secondary to treatment were a concern. Change. Negative change Fear of recurrence. No guarantee of tomorrow. Chronic illness. Post-diagnosis growth consistent with all participants. All participants stated were focusing on living not dying. Agency/Voice

**Appendix B Flyer**

# **Have you had Breast Cancer?**

**If you are over the ages of 18 and have completed treatment for breast cancer more than 5 years ago, you may be eligible to participate in a breast cancer research study. As a participant you would be asked about your experience since you left treatment for breast cancer and what has helped you survive and what difficulties were experienced. The information from this study will be used to help health care workers understand survivors' experiences . Participants will receive a \$20.00 gift card to a local grocery store for an interview lasting approximately one hour.**

**If you are interested in participating,**

**Please contact:**

**Jennifer Klimek Yingling**

**At**

**315-725-9581 or [jky18@msn.com](mailto:jky18@msn.com)**

## Appendix C Rutgers IRB

RUTGERS UNIVERSITY  
Office of Research and Sponsored Programs  
ASB III, 3 Rutgers Plaza, Cook Campus  
New Brunswick, NJ 08901

July 26, 2012

P.I. Name: Yingling  
Protocol #: 12-765M

Jennifer Klinck Yingling  
28 Pineview Drive  
Utica NY 13502

Dear Jennifer Klinck Yingling:

( Initial / Amendment / Continuation / Continuation w/Amendment )

**Protocol Title:** "Grounded Theory of the Survivorship Process in Women Who Have Completed Treatment for Breast Cancer"

This is to advise you that the above-referenced study has been presented to the Institutional Review Board for the Protection of Human Subjects in Research, and the following action was taken subject to the conditions and explanations provided below:

<b>Approval Date:</b>	7/5/2012	<b>Expiration Date:</b>	7/4/2013
<b>Expedited Category(s):</b>	6.7	<b>Approved # of Subject(s):</b>	20

This approval is based on the assumption that the materials you submitted to the Office of Research and Sponsored Programs (ORSP) contain a complete and accurate description of the ways in which human subjects are involved in your research. The following conditions apply:

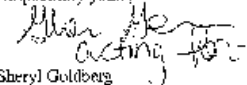
- **This Approval**—The research will be conducted according to the most recent version of the protocol that was submitted. This approval is valid **ONLY** for the dates listed above.
- **Reporting**—ORSP must be immediately informed of any injuries to subjects that occur and/or problems that arise, in the course of your research;
- **Modifications**—Any proposed changes MUST be submitted to the IRB as an amendment, for review and approval prior to implementation;
- **Consent Form(s)**—Each person who signs a consent document will be given a copy of that document, if you are using such documents in your research. The Principal Investigator must retain all signed documents for at least three years after the conclusion of the research;
- **Continuing Review**—You should receive a courtesy e-mail renewal notice for a Request for Continuing Review before the expiration of this project's approval. However, it is your responsibility to ensure that an application for continuing review has been submitted to the IRB for review and approval prior to the expiration date to extend the approval period.

**Additional Notes:** Expedited Approval per 45 CFR 46.110

**Failure to comply with these conditions will result in withdrawal of this approval.**

Please note that the IRB has the authority to observe, or have a third party observe, the consent process or the research itself. The Federal-wide Assurance (FWA) number for the Rutgers University IRB is FWA00002913; this number may be requested on funding applications or by collaborators.

Respectfully yours,

  
Sheryl Goldberg  
Director of Office of Research and Sponsored Programs  
gir3@grants.rutgers.edu

cc: Elise L. Lev

**Appendix D IRB FSLHC****IRB  
INSTITUTIONAL REVIEW BOARD****OF****FAXTON-ST. LUKE'S HEALTHCARE**

Jennifer Klimek Yingling PhDc, APRN, ANP-BC, FNP-BC

September 7, 2012

28 Fineview Drive,

Utica, NY 13502

RE: **GROUNDING THEORY OF THE SURVIVORSHIP PROCESS IN WOMEN WHO HAVE COMPLETED  
TREATMENT**

Dear Jennifer Klimek Yingling,

The Institutional Review Board (IRB) of Faxton - St. Luke's Healthcare is pleased to inform you that it has conducted the initial review and has approved study: GROUNDING THEORY OF THE SURVIVORSHIP PROCESS IN WOMEN WHO HAVE COMPLETED TREATMENT at a full board meeting held on September 6, 2012. The Consent Form was also approved.

*This approval expires 9/5/2013*

All subjects entered onto the study during the forthcoming year must be given a copy of the IRB approved consent to the subject and to also place a copy in the patient's chart.

You are required to notify this IRB whenever the scope of your study changes significantly, whenever local serious adverse events occur or whenever the study is being terminated.

The IRB will continue to review this protocol at an interval of not less than once per year, as well as whenever new findings result from this study or changes (other than administrative or editorial) occur in the protocol.

This Institutional Review Board subscribes to and functions within the requirements of *Title 45 of the Code of Federal Regulations, Part 46, "Protection of Human Subjects"*.

If you have any questions, please contact the Office of the IRB at (315) 624-5705.

Sincerely,

Christie Kozyra RHIA, CTR  
Coordinator Oncology Information Management



**Appendix E General Consent Form****INFORMED CONSENT FORM**

You are invited to participate in a research study that is being conducted by Jennifer Klimek Yingling, who is a graduate student, as part of a doctoral dissertation at the College of Nursing at Rutgers, the State University of New Jersey in Newark, New Jersey. The purpose of this research is to investigate the process of transitional survivorship from the perspective of women who have completed initial treatment for breast cancer. The goal of this study is to obtain information that will help other women who have had breast cancer and healthcare providers who treat them understand issues in the extended survivorship stage.

Approximately 10 subjects between the ages of 18 and 99 years old will participate in the study, and each individual's participation will last approximately 2 hours.

Participation in this study will involve the following: completion of a demographic survey and participate in a one hour interview.

This research is confidential. The research records will include some information about you and this information will be stored in such a manner that some linkage between your identity and the response in the research exists. Some of the information collected about you includes: age, marital status, education background, employment, time that subject was told had breast cancer, length of treatment for breast cancer. Please note that we will keep this information confidential by limiting individual's access to the research data and keeping it in a secure location.

The research team and the Institutional Review Board at Rutgers University are the only parties that will be allowed to see the data, except as may be required by law. If a report of this study is published, or the results are presented at a professional conference, only group results will be stated. All study data will be kept for three years after the completion of the study.

Risks of participating in this study include the potential for psychological distress related to the elicitation of emotions based on past experiences. Arrangements for stand-by psychological counseling will be made if needed with a Dr. Joanne Joseph, a psychologist who has had extensive expertise working with this population.

You have been told that the benefits of taking part in this study may be: the discussion of the social experience and disease establish a venue in which a voice is provided to the extended survivor to generate purpose, catharsis, affirmation, empowerment, and healing. However, you may receive no direct benefit from taking part in this study. You will receive the participants in this study will be given a \$25.00 gift card to a local grocery store as compensation for completing the entire study. The honorarium will be granted even if the participant withdraws from the study.

Participation in this study is voluntary. You may choose not to participate, and you may withdraw at any time during the study procedures without any penalty to you. In addition, you may choose not to answer any questions with which you are not comfortable.

If you have any questions about the study or study procedures, you may contact:

Jennifer Klimek Yingling: 315-725-9581 (cellular) or 315-724-4601 (home).

If you have any questions about your rights as a research subject, you may contact

the IRB Administrator at Rutgers University at:

Rutgers University, the State University of New Jersey

Institutional Review Board for the Protection of Human Subjects

Office of Research and Sponsored Programs

3 Rutgers Plaza

New Brunswick, NJ 08901-8559

Tel: 848-932-0150

Email: [humansubjects@orsp.rutgers.edu](mailto:humansubjects@orsp.rutgers.edu)

You will be given a copy of this consent form for your records.

Sign below if you agree to participate in this research study:

Subject (Print) \_\_\_\_\_

Subject Signature \_\_\_\_\_ Date \_\_\_\_\_

Principal Investigator \_\_\_\_\_ Date \_\_\_\_\_

**Appendix F Demographic Fact Sheet**

**Demographic Fact Sheet**

ID:

Age:

Ethnic origin:

Marital Status: married

Educational Background: Employment Status: full time/part time/not employed/retired

**Breast Cancer Information:**

When were you first told you had breast cancer? Give month and year

How long were you in treatment? Give month and year from beginning to end of treatment.

What treatment did you undergo?

List surgery (types), chemo, radiation, hormonal etc. list time periods

**Appendix G Audio Consent****AUDIO/VIDEOTAPE ADDENDUM TO CONSENT FORM**

You have already agreed to participate in a research study entitled: Grounded Theory of the Survivorship Process in Women who have Completed Treatment for Breast Cancer conducted by Jennifer Klimek Yingling. We are asking for your permission to allow us to audiotape the interview as part of that research study. You do not have to agree to be recorded in order to participate in the main part of the study.

The recording(s) will be used for analysis by the research team and possible use as a teaching tool to those not part of the research team for educational purposes. The audio tapes will not be used for commercial purposes and the subject will not be compensated.

The recording(s) will include a identification code recorded by the principal investigator to preserve confidentiality. The participants will be identified solely by number documentation. Personal identifying information will not be linked during transcription and the interview process. The participants will be informed of this process and the anonymity of participants will be protected will be informed that comments made may be reported in the final study, but would be presented in a manner to protect anonymity. Files that contained participant identifying information and personal contact information will be stored in a separate locked file discrete and distinct from the area in which the research data will be stored.

The recording(s) will be stored in a locked file cabinet and linked with a code to subjects' identity and will be stored for three years after the completion of the study. All audio recording will be destroyed by shredding three years after the completion of the research. Research files and information will be kept in a double locked area, accessible only to the primary researcher until three years after the completion of the study. At this time the written and audio data will be shredded. Your signature on this form grants the investigator named above permission to record you as described above during participation in the above-referenced study. The investigator will not use the recording(s) for any other reason than that/those stated in the consent form without your written permission.

Subject (Print)\_\_\_\_\_

Subject Signature \_\_\_\_\_ Date \_\_\_\_\_

Principal Investigator \_\_\_\_\_ Date \_\_\_\_\_

## **Appendix H Interview Guide**

### **Interview Guide**

Discuss your feelings about returning to your primary care healthcare provider.

What physical outcomes do you continue to have?

What emotional outcomes do you continue to have?

Do you see a primary care health care provider?

How often do you see your health care provider?

What training does your health care provider have...MD, DO, APRN, RPA?

Talk about your health care provider and the care you received.....MD, DO, APRN, RPA?

Who helped you deal with the physical outcomes of cancer treatment?

Who helped you deal with the emotional outcome of cancer treatment?

When did you feel that you moved from dealing with the issues concerning your cancer treatment to dealing with issues related to living with your cancer?

What challenges do you face regarding living with your cancer?

Are there other issues you want to discuss that are related to your cancer?

## Appendix I Memos/Journal

### List of all memos

Memo-Filter: All [62]

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HU: Process of breast cancer survivorship 102112  
 File: [C:\Users\Nursing\Documents\Scientific Soft...\Process of breast cancer survivorship 102112.hpr7]  
 Edited by: Super  
 Date/Time: 2012-12-30 20:35:35

---

#### **MEMO: after interview (0 Quotations) (Super, 2012-09-18 01:05:06)**

Codes: [family hurting - Families (2): Family Roles, Support Family Hurting]

No memos

Type: Commentary

Subject one said she is kind of tired of daughter always making her things with pink ribbons on them. Also said when found out her diagnosis went to be with friends and though afterwards she probably should have stayed home to be with husband as he probably needed to be comforted.

#### **MEMO: acquaintance support (0 Quotations) (Super, 2012-09-13 14:16:29)**

No codes

No memos

Type: Commentary

Light bulb went off idk acquaintance support was in interview 1 and 4 and 5- out of the blue

#### **MEMO: aware of timing when disclosing dx (0 Quotations) (Super, 2012-10-05 16:29:02)**

No codes

No memos

Type: Commentary

this is huge finally a hcp that got this right, well in interview 9 the hcp was good about that too but I remember interview 1 hello you have bc and I am on vacation. I think there is something to this...there seems to be an immediacy to act after the BC dx is confirmed.

#### **MEMO: BC as a learned experience (1 Quotation) (Super, 2012-09-08 12:33:23)**

P 1: jky subject 172712 transcribed interview rtf.rtf:

(63:63)

No codes

No memos

Type: Commentary

I feel like Carrie Bradshaw typing like this, just putting my thoughts out there. Ok now twice participant 1 talked about fear because didn't know anyone who had experience BC and now talks about wanting to share what she learned from her experience with BC with newly



diagnosed BCS. Is the experience of BCS a learned experience? Maybe. Learned behavior? IDK

**MEMO: Being a new patient (1 Quotation) (Super, 2012-09-08 11:38:06)**

P 1: jky subject 172712 transcribed interview rtf.rtf:

(44:44)

No codes

No memos

Type: Commentary

Being a new patient seems to cause duress? Now knowing the provider taking care of you is this something that affects the survivors? New experience of seeking answers with someone they don't know or have built trust with. Hmm IDK just a thought.

**MEMO: beside self (0 Quotations) (Super, 2012-09-18 18:05:30)**

No codes

No memos

Type: Commentary

It refers to an uncommon elevated state of excitement, good or bad.

"Beside" was formerly (15th through 19th centuries) used in phrases to mean "out of a mental state or condition,

**MEMO: connecting with HCP over something common (0 Quotations) (Super, 2012-10-04 16:50:42)**

No codes

No memos

Type: Commentary

Ok this happened in interview 7 too

BCS connected with HCP because both had children of the same age

This on BCS connected with HCP because both had lost mother

I guess as providers and patients we forget that each is human and has other roles in life....connecting over birth and death both a very human process that evens the playing field per se. Both birth and death aren't affected by professional or personal illness roles. Hmmm. I think BCS and patients in general crave to see the human side of HCP, to know they are human just like me maybe

**MEMO: control (0 Quotations) (Super, 2012-09-18 00:35:16)**

No codes

No memos

Type: Commentary

I think it came from not having any control over the disease but I felt like I lost control over my entire life. I think this is profound.

**MEMO: deciding which HCP will see after treatment (0 Quotations) (Super, 2012-10-04 11:05:42)**

No codes

No memos

Type: Commentary

These women talk about all the follow up appointments. I kind of feel like they triage out what is

important, maybe they think PCP isn't important while they are seeing the ONC team. Unfortunately the ONC team is scattered in the sense they may go to ONC, Surgeon and radiologist and OBGYN all for the same problem. I guess maybe do they perceive quantity for quality and the specialists they see, not a one of them assumes the role of air traffic controller and may not even be in contact with each other. The specialists are focusing on the BC not treating the BCS holistically. So what about preventive stuff bone density hTN etc. or better yet the psych component? It is kind of like tag...I wonder if they assume another provider is providing this stuff. Disconnect...hmmm maybe going back to the PCP should be encouraged by the entire specialist and they shouldn't take for granted the BCS will do this on their own. Need to puff chest as a credible authority to make sure everything else health wise is taken care of too! OK being an opinionated ER NP but I see the disconnect in these interviews and in my patients when the problem they have has immediacy. PCP is underrated lol

**MEMO: desire to help others (1 Quotation) (Super, 2012-09-08 12:27:13)**

P 1: jky subject 172712 transcribed interview rtf.rtf:

(61:61)

No codes

No memos

Type: Commentary

Interesting to me that BCS go to the assistance of new BCS even if they don't know them????  
Some kind of kinship maybe, feels connected because of common diagnosis IDK

**MEMO: double whammy (0 Quotations) (Super, 2012-10-02 23:29:48)**

No codes

No memos

Type: Commentary

ok a thought in a previous illness the subject talked about husband being worked up for prostate CA at same time was starting treatment, this subject also had a double whammy her husband unexpectedly became unemployed.

**MEMO: duh that was a good one (0 Quotations) (Super, 2012-09-13 14:50:45)**

No codes

No memos

Type: Commentary

Hope I didn't offend her by not knowing one of the rock stars of BC. I went to the state fair since and you should have seen the display they had huge with pink banners couldn't miss it. And I met Carol Baldwin myself and no she doesn't have any implants just like subject 5 said. It is funny how the researcher's eyes are opened. I have ER background and current practice so I didn't see I guess wasn't interested in all of the BC stuff. I guess I now have rose colored glasses-hmm good metaphor. Well I guess I want to talk about what I have been seeing myself in the community. So talked about state fair. I have been there several times and saw this stuff but this time really SAW it I guess. I also have reached out to the local ABC group. Had to do IRB at FSLHC which was an eye opener, not like Rutgers LOL! But I have been an employee for 19 years and really didn't know who was doing any research here in Deliverance, NY. Was surprised one of the pediatricians I hold in high esteem working on research with lead, really high levels in this area compared to the state? I guess I am a researcher-kind of the imposter theory in vivo I suppose. Also met the head of the ABC group, I am going there on Saturday to talk to the women. Trying to hold this all in as Barney Glaser talks about I think the core variable is stress. I am frustrated at how slow this process is and it has been very hard to code in peace with my school and most of

all family obligations. Thought of sugar plum codes dance in my head. I was to get done, I am accepting that this process takes time and that is hard when you are a type A plus with OCD tendencies, not diagnosed for the record. I am scared to go see Dr. Glaser in October; I think I will get dinged for using this program. But I am using this as my trapper keeper. All of the coding is all me not the program. Head spinning have caught self-feeling lost much to do and not enough time. I am also accepting the fact that I may not get re-appointed but after all I have done and given up if SUNY doesn't see what I am worth then they don't deserve me and PhDs in nursing on the east coast are not a dime a dozen. Why am I going off? I am lonely in my experience I guess. And best of all threading through this whole dissertation experience I had an abnormal mammo myself...and kept thinking this would be poetic justice. I am trying to keep my own thoughts at bay as I was done nasty too. A lot of worry for nothing all because the radiologist said I don't know what this is. I was scared because my friend was sick and her experience. I do think young women get blown off especially if they are under 40. True story. Just saying LOL! OK now I got this stuff out and need to progress further dear dissertation or I will never get on that cruise ship. Guess better start preparing as it may just happen.

**MEMO: educators (1 Quotation) (Super, 2012-09-09 23:00:37)**

P 4: jky subject 481412 transcribed interview rtf.rtf:  
(104:166)

No codes  
No memos  
Type: Commentary

It just struck me that bcs are educating their family and other survivors-powerful making it better for others

**MEMO: empathy (0 Quotations) (Super, 2012-09-18 14:04:24)**

No codes  
No memos  
Type: Commentary

This is a second time a subject talked about understanding...I think empathy. Empathy from spouse about physical and mental symptoms, empathy from other BCS, empathy from society, empathy from HCP  
I looked up sympathize in thesaurus can mean understand. Maybe on to something.

**MEMO: employment (0 Quotations) (Super, 2012-09-18 19:16:06)**

No codes  
No memos  
Type: Commentary

In a previous interviews employment as a distraction (sub 1), source of stress (sub 5) encouragement (sub 6) a vehicle for change and learning (sub 3)

**MEMO: family roles (0 Quotations) (Super, 2012-10-02 15:24:53)**

No codes  
No memos  
Type: Commentary

In this interview family roles were very evident. Comparing back they also were evident in interview 1, 2,3,5,6 & 7. This subject was childbearing and rearing during finding abnormality to treatment to finding out pregnant again. Roles of the mother seem to be important.

**MEMO: finding out had breast cancer (1 Quotation) (Super, 2012-09-09 15:28:35)**

P 2: jky subject 280112 transcribed interview rtf.rtf:

(67:71)

No codes

No memos

Type: Commentary

Even though this study is focusing on the time period of once treatment ends this is the second time the subject noted the time when was told had breast cancer as significant. IDK maybe there is something here. Just a thought.

**MEMO: Flight of thoughts (0 Quotations) (Super, 2012-09-08 12:43:38)**

No codes

No memos

Type: Commentary

I just had a thought. For this BCS she is young so none of her peers have gone through his experience so this may be different that older BCS. Like pregnancy, I think of myself a lot of my friends have gone through this and I know we talked about the physical and emotional things, advice through at and given out from the lived experience. In older women more of their peers may have gone through this purely because of the prevalence of the condition in older women. IDK just a thought. Women whisper about body issues to each other, reassure each other for example like in pregnancy and childbirth or breastfeeding...kind of a kinship. They seek out answers from each other. IDK just a thought a memo...my schizophrenic memos.

**MEMO: grapevine and similarities of interview 1 and 5 (0 Quotations) (Super, 2012-09-13 14:47:13)**

No codes

No memos

Type: Commentary

I keep going back to look at codes re-coding interview 1 and 5 and also 4, Comparing is huge. Grapevine is a developing concept I think in the other interviews they talked about hearing stories from other people, not really gossip but not sure yet almost like there is an informal education network...survivors going to other survivors because of common thread- BC this interview points out that survivors also see outcomes. Just a though dear dissertation.

**MEMO: happy dead survivors (0 Quotations) (Super, 2012-09-15 17:44:13)**

No codes

No memos

Type: Commentary

I don't know how to articulate this one. Sees picture of a survivor that is happy survived cancer then that same survivor dies. IDK but this may be something. Survivor guilt another part IDK

**MEMO: hcp advice (0 Quotations) (Super, 2012-09-13 13:27:22)**

No codes

No memos

Type: Commentary

In interview 4 and 5 advice of hcp weighed heavily on survivor as did the no professional advice of others

**MEMO: HCP changed (0 Quotations) (Super, 2012-09-13 16:40:23)**

No codes

No memos

Type: Commentary

In subject 5 interview talked about HCP changing also in interview 4

**MEMO: HCP saying if you were my wife or mother (0 Quotations) (Super, 2012-10-05 15:09:11)**

No codes

No memos

Type: Commentary

This happened in a previous interview where the BCS needed a plastic surgeon and he sent her to the surgeon who did his mothers. This HCP said if you were my wife...first of all what about evidenced based care never mind the emotional piece. DO HCP sway patients into treatments by saying this, is this an attempt to personify the BCS. These phrases seem to disclose the humanness of the HCP, he cares for me like family the BCS thinks IDK

**MEMO: health promotion model (0 Quotations) (Super, 2012-09-18 14:20:03)**

No codes

No memos

Type: Commentary

LOL this PA must have read Nola Pender...way to go a perfect example of HPM

**MEMO: I cried (0 Quotations) (Super, 2012-09-18 21:31:44)**

No codes

No memos

Type: Commentary

OK this part of the interview I got choked up. Thinking of the unconditional love a parent has for a child no matter what age they are. I related to this statement as a daughter and mother. Then I thought of my dad, he and I are close and he is non-medical and analytical the facts are the facts and he would say the same thing. I think if I got emotional maybe this is important...I take pride in being a strong ER nurse I don't cry. LOL but this dissertation is making me want to!

**MEMO: I feel like I know these people (0 Quotations) (Super, 2012-09-19 00:09:07)**

No codes

No memos

Type: Commentary

I think was a profound statement

**MEMO: I have had BC (0 Quotations) (Super, 2012-10-05 15:19:18)**

No codes

No memos

Type: Commentary

This has come up several times in the interviews.

**MEMO: immediacy linked with stress (0 Quotations) (Super, 2012-09-18 17:52:15)**

No codes

No memos

Type: Commentary

Another theme emerged in this interview immediacy it was in interview 1 to start treatment, in interview 5 the informal neighbor HCP recognized need to get mammo, in interview 3 when needing psych help.

Flipping out freaking out upset emotions all over the place= mental duress

**MEMO: information may scare survivor (0 Quotations) (Super, 2012-09-13 14:41:02)**

No codes

No memos

Type: Commentary

Information may scare survivor

**MEMO: interview 2 (0 Quotations) (Super, 2012-09-28 02:04:31)**

No codes

No memos

Type: Commentary

Memo August 1, 2012

I feel like the second interview was harder the subject wasn't as verbose as the first interview that I did once again I felt like the fear of reoccurrence was prevalent additionally in regards to health care providers the interaction played a very important part in the satisfaction of the subject as the subject above mentioned that primary care provider listens she said he will sit down and listens. was important but surely the family was very important as well in the second interview was hard because I had to use a lot of prompting to get subject to all expelled under answers was almost like she wanted to answer the questions like a questionnaire so that was hard in this interview. Being a Monday morning quarterback on self when I was transcribing felt like could have probed more...weird vibe. But even if less data still had pertinent information to add to the study.

**MEMO: learned expectations (0 Quotations) (Super, 2012-10-03 13:56:39)**

No codes

No memos

Type: Commentary

Hmmm learned expectations...again learning from past experience better than any book I suppose

**MEMO: learning (0 Quotations) (Super, 2012-10-03 13:13:35)**

No codes

No memos

Type: Commentary

BCS are constantly learning from internet, peers, HCP. Is adapting to BC a learned behavior?

**MEMO: linger (0 Quotations) (Super, 2012-09-18 00:04:53)**

No codes

No memos

Type: Commentary

Ok interview 1 was upset at way told dx. This subject still talking about miss-diagnosis (scary to me). Others previously talked about how wonderful the provider informal and formal were in helping them get testing or how were told compassionately and went out of way to tell diagnosis. This time frame in the survivorship trajectory seems to have lingering after effects both subject 1 and 6 are 3mth out and 2 years out....hmmm.

**MEMO: little baskets (0 Quotations) (Super, 2012-10-04 23:56:20)**

No codes

No memos

Type: Commentary

The survivor thought this was dehumanizing the radiation baskets. I think this is bigger than just the baskets. First the masking tape, not permanent reusable. Did this bother the BCS because of the amount to baskets she saw, was it the number of baskets that had names on them that put a name on cancer? was it because the tape could get taken off when someone died then replaced with someone who was new to cancer, was it seeing the dead girl's name. Was it the disregard that the cancer survivors only personal item that was kept at radiation was cared for did she equate this to how she perceived she was being cared for? Was it that she felt like it was a factory like setting? IDK Keep having the weeds song run in my head when I listen and read this little houses...

**MEMO: living life after BC (0 Quotations) (Super, 2012-10-03 14:54:11)**

No codes

No memos

Type: Commentary

I was just going along, living my life and doing ordinary things. In the previous interview same thing.

**MEMO: looking good with clothes on (0 Quotations) (Super, 2012-09-13 14:35:01)**

No codes

No memos

Type: Commentary

Looking good with clothes on and a mess physically underneath. Just a thought

**MEMO: loss of control over illness (0 Quotations) (Super, 2012-10-02 23:36:59)**

No codes

No memos

Type: Commentary

ding ding ding in the previous interview the subject talked about not stressing over thing you can't control, getting mad over loss of control...is this accepting loss of control of the illness. Controlling things you can kind of like serenity prayer god grant me the wisdom...they get a primary after dx and treatment. To accept the things I cannot change (maybe is the turning point for BCS) change the things I can (taking control of health, emotions family) and the wisdom to know the difference. I am not sure why this prayer pops up everywhere when Pat died when I was 9 my mom had us read this. Was an embroidered picture in her sewing room....no she is not a member of AA loam! I wrote a paper titled the same The same exact embroidery was in the ER on the wall in the nurses desk at my first job as a NP...maybe I am destined to be a member of AA. On a serious note this stinking prayer has chased me around my whole life and her it is again

maybe. IDK

**MEMO: luck (0 Quotations) (Super, 2012-09-13 14:01:11)**

No codes

No memos

Type: Commentary

Luck in this interview luck equated with comparisons of others experiences

**MEMO: mammo false sense of safety (0 Quotations) (Super, 2012-10-04 10:33:00)**

No codes

No memos

Type: Commentary

This has come up in interview 6 having mammo read as normal may not be as these women had BC. IDK just a thought dear dissertation

**MEMO: moving on (1 Quotation) (Super, 2012-09-09 17:06:19)**

P 3: jky subject 380712 transcribed interview rtf.rtf:

(89:89)

No codes

No memos

Type: Commentary

In this interview the subject articulates that family, friends and society participation helped her move on. Are these aspects that the BCS draws strength from?

**MEMO: No HCP during treatment (0 Quotations) (Super, 2012-09-18 14:17:17)**

No codes

No memos

Type: Commentary

Hmm maybe this is where it starts, BCS have onc team while sick and maybe this is where the disconnect starts. Kind of like out of sight out of mind.

**MEMO: office staff actions important (0 Quotations) (Super, 2012-10-04 17:05:38)**

No codes

No memos

Type: Commentary

OK office staff and their impact were present in interview 1 office changing no phone calls back. Interview 2 liked female radiology techs. Interview 4 noted the office she enjoyed going to had friendly office staff. In this interview the ultrasound tech was a beautiful liar and later the radiology tech compromised the confidence that the BCS had in the HCP by saying he doesn't know what he is doing. I guess we need to be sure that everyone who is in contact with BCS is aware of how they impact the emotional well-being of the patients. Even small actions and words or no words can help or hurt.

**MEMO: ONC vs. PCP (0 Quotations) (Super, 2012-09-13 16:26:54)**

No codes

No memos

Type: Commentary



Do BCS think the PCP can't handle them after their experience? Do they not want to participate in routine care after spending so much time with onc team? IDK

**MEMO: opposites (0 Quotations) (Super, 2012-10-03 15:35:13)**

No codes

No memos

Type: Commentary

Ok a thought

Some talk some don't

Some wear pink ribbons some shun them

Some say are victims other survivors

There are many more in this data a place to explore

**MEMO: P3 memo after interview (1 Quotation) (Super, 2012-09-09 18:21:55)**

P 3: jky subject 380712 transcribed interview rtf.rtf:

(106:107)

No codes

No memos

Type: Commentary

8/7/12 memo

Great interview. Subject 3 was amazing. Fear of recurrence, physical symptoms, concept of moving on, helping others, and putting cancer on back burner and friends/family support common in all three so far. To tire tonight to code, will do in am as felt interview 2 was sparse. Started with atlas ti. Do like coding with it so far, want to get some diagnostics. Would like to print out the codes from each interview out and or see common codes...homework for the weekend. Hope Dr. Lev has some tips. Going to see Dr. Lev Thursday. I am really happy with progress; I have another interview scheduled for Friday. So 4 in 2 weeks. Also Glaser's conference in NYC...yeah not flies October 19<sup>th</sup>. Additionally the pressure off from school for an additional year. Kind of mad about that as I want this dissertation and continuing apt over with. Have to concentrate on fall course a little this weekend. Interview 2 was a bit disappointing subject wanted to answer yes no and didn't really expand...I guess that is how it is with different personalities. I was a Monday morning quarterback to self and I could have probed more with questions. I guess that is part of the process.

**MEMO: physical scars fade but do the emotional scars? (0 Quotations) (Super, 2012-09-09 21:27:46)**

No codes

No memos

Type: Commentary

This subject talks about how her physical scars are minimal yet her emotional scars are apparent.

**MEMO: protection (0 Quotations) (Super, 2012-10-03 14:18:14)**

No codes

No memos

Type: Commentary

There it is you have certain protection she said it. While in treatment protected and when leave that protection is gone. Also doing something to kill cancer when done with Rx are no longer

actively fighting well quantitatively active

**MEMO: put back together (1 Quotation) (Super, 2012-09-08 10:46:22)**

P 1: jky subject 172712 transcribed interview rtf.rtf:

(21:21)

No codes

No memos

Type: Commentary

Idk why but feel like survivor may feel like humpty dumpty and need to be put back together in order to move on

**MEMO: random thoughts 927 (0 Quotations) (Super, 2012-09-28 02:03:37)**

No codes

No memos

Type: Commentary

The serenity prayer giving and taking empathy accepting and moving on

Accepting loss of control

Stressors and Buffers

Part of life

Choices

Comparing

These are just some of my random thought and I am driving in my car and I am using Siri to transcribe this memo bec

**MEMO: recurrence (0 Quotations) (Super, 2012-10-03 13:57:28)**

No codes

No memos

Type: Commentary

*"Only Thing We Have to Fear Is Fear Itself": FDR's First Inaugural Address*

Almost all talk about fear of recurrence then when it happened here was not surprised or shocked. I guess if recurrence happens then the mental pressure stress off nothing to fear anymore,

**MEMO: repairing relationships (0 Quotations) (Super, 2012-10-04 16:59:13)**

No codes

No memos

Type: Commentary

This is an example of BCS not having a good initial interaction with HCP, asserting her power of change and seeking another provider. The second opinion was much more negative. Asking surgeon to mediate situation. Going back to the HCP. Now what is interesting is that I don't think many patients address the situation as directly. HCP welcomed the conversation and they moved on to get the radiation done. Maybe this need to happen more. BCS had empathy for HCP over death of mother, a common situation. I guess maybe this should happen more on both sides. Patients remembering the HCP is human and likewise HCP remembering BCS also human not just another patient in the exam room. Interview 5 talked about the surgeon having tears in his eyes when he told her the news. But it was negative in interview 1 as the surgeon told the patient he

was on vacation so maybe too much info is bad too.

**MEMO: staging information (1 Quotation) (Super, 2012-10-05 11:05:11)**

P15: jky subject 1192912 transcribed interview.rtf:

(102:102)

No codes

No memos

Type: Commentary

Staging information then when I come back to see you, we can talk about other things, let me deal with this (reality of mets) first and then when I come back to see you we can talk about other things.....the BCS here chose to stage her information. She is a simple girl but wise in many ways. Another BCS decision

**MEMO: support that is present medically (0 Quotations) (Super, 2012-10-04 23:16:52)**

No codes

No memos

Type: Commentary

OK seems like if you have a nurse in the family or a friend there may be an advantage to your support system...interesting the term present medically. Like an extra invested medical advocate besides the hcp taking care of the BCS. Interesting too the informal role nurses have played in this and interview 5 where the neighbor nurse facilitated a lightning fast mammo appointment and encouraged BCS to get abnormality screened. Additionally in this interview the chiropractor encouraged the BCS to get the abnormality screened....I tell my students get ready you are already and it gets worse if people know you have an advanced degree that people acquaintances family member will look to you for medical advice as a credible authority. Well I am proud of these nurses in the interviews who went the extra mile and helped the BCS.

**MEMO: surgeons for follow up (0 Quotations) (Super, 2012-10-03 14:25:51)**

No codes

No memos

Type: Commentary

OK not to beat down surgeons but they are an interesting group...I have worked with many and I think it may be a personality trait that attracts individuals to this line of work. Assertive reactive work predominately with tasks on intubated people so it stands to reason there may be some difficulty with surgeons and female BCS as the breast cancer survivors as sometimes the polar opposite personality wise. IDK flight of thoughts. I guess too it may be hard for them to switch modes from intense, lifesaving tasks to talking about feeling; getting asked questions all that fluffy stuff.

**MEMO: swirling (0 Quotations) (Super, 2012-10-02 14:17:42)**

No codes

No memos

Type: Commentary

Swirling after treatment, kept busy with doctors' visits during RX. Hmm maybe profound. Seems to me a one stop shop might be warranted for these BCS as they are going all over town to different providers onc, radiologist obgyn. I guess multidisciplinary clinic would be good. Have to wonder as a provider if there is replication of services. And maybe childbearing women have different time constraints and responsibilities. Kind of feel they get HCP fatigue and need a one

stop shop. IDK my thoughts

**MEMO: transition from CA to general health (0 Quotations) (Super, 2012-10-04 11:17:01)**

No codes

No memos

Type: Commentary

Well there it is a transition from BC to General health

**MEMO: trivial thing one thing that can control (0 Quotations) (Super, 2012-10-04 14:33:27)**

No codes

No memos

Type: Commentary

This is interesting in interview 6 the control was picking out heaters in interview 7 she controls her family.

**MEMO: Trying to make sense (0 Quotations) (Super, 2012-09-18 20:28:55)**

No codes

No memos

Type: Commentary

Luck and God is maybe what BCS use to make sense out of illness. A lot of references to luck accepting that nothing influences outcomes just random and they landed on the right side of the coin. Two sided coin good outcome/bad outcome. IDK random thoughts. Gambling when we don't have control of the illness. Hahaha Carrie Bradshaw came out again!

**MEMO: wandering (0 Quotations) (Super, 2012-10-02 13:59:27)**

No codes

No memos

Type: Commentary

Not going back to PCP is this the same as subject 3 wanting to just leave...wandering after treatment idk

**MEMO: words are important (0 Quotations) (Super, 2012-09-15 20:30:54)**

No codes

No memos

Type: Commentary

In this interview the choice of words: disease precaution weighed heavily on the BCS and her decisions

**MEMO: wow times have changed (0 Quotations) (Super, 2012-10-03 12:33:31)**

No codes

No memos

Type: Commentary

I have to think after listening again to this interview that thank god times have changed. This "old school" surgeon scared the spouse and promoted isolation. He would be lynched in this day and age. It is interesting to me as in the healthcare environment currently it is important for HCP to be balances skillful with people skills. Blows my mind that support groups were discouraged. I have to wonder again about breast cancer as a learned experience, maybe the current survivors

still have scars of the last generations experiences? IDK. I am sure these types of behaviors didn't help increase the fear of BCS. Also she talked about going to surgery for a bx and waking up with a mastectomy, not having to sign for own procedure WOW how scary. Glad BCS of the past have advocated for change. I also think if I traveled back in time as the nurse I am today I would be fired lol! I am a patient/family advocate to the core. Not sure who this surgeon was but an old school surgeon I worked with comes to mind when he wanted to lace me up for allowing a post op patient who I was covering during lunch time has a straw on his lunch tray. He was super intimidating and the only person I was saved by was another surgeon who knew me and my aunt was an office manager for. I remember how scared I was of him, how I felt when I "crossed him" per se and can't imagine how this patient felt. Today the hospitals send them for anger management training when they act out hehehehe!

**MEMO: writing as an outlet (0 Quotations) (Super, 2012-10-03 15:31:52)**

No codes

No memos

Type: Commentary

In another interview the BCS wrote a book this is an outlet of the experience maybe interview 3

## Appendix J. Final Code List Output

### Code-Filter: All

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HU: control 111612  
 File: [C:\Users\Nursing\Documents\Scientific Software\ATLAS\i\TextBank\control 111612.hpr7]  
 Edited by: Super  
 Date/Time: 2012-12-30 20:40:20

---

**Accept**  
**Accepting cannot control Cancer**  
**Angry over missed diagnosis**  
**Appointments causes fear of recurrence**  
**Attitude I think if I do get it again I can deal with it.**  
**Attitude positive**  
**Avoiding Cancer events as are reminders of mortality**  
**BCS distracting self with employment**  
**BCS distraction family roles**  
**BCS distraction martial roles**  
**BCS learning about self**  
**BCS social comparison**  
**BCS taking control by educating self**  
**BCS taking control of actions**  
**BCS taking control of care**  
**BCS taking control of diet**  
**BCS taking control of emotions**  
**BCS taking control of exercise**  
**BCS taking control of family**  
**BCS taking control of self-education internet**  
**BCS taking control of self-education seminars**  
**BCS taking control of timing of ADLs to accommodate optimal functioning**  
**BCS taking control of weight**  
**Blood work causes fear of recurrence**  
**Body image causes emotional distress**  
**Bringing abnormality to hcp and getting misdiagnose**  
**Cancer impacts family**  
**Caring**  
**Because they say your life goes...**  
**Complementary therapies**  
**Continuing physical Sx**  
**Couldn't deal with life anymore..**  
**Counseling group**  
**Cutting point acceptance it is what it is**  
**Cutting point cancer is back**  
**Cutting point Completing treatment**  
**Cutting point confirming DX**  
**Cutting point in treatment**  
**Cutting point is cancer back**  
**Cutting point waiting for DX confirmation**  
**Cutting point waiting to start treatment**  
**Diagnosis doesn't stop life**  
**Didn't know who I was, where I..**

Different levels of acceptance..  
Different levels of fear  
Disclosing Survivorship status  
Doctored out  
Don't want constant reminders of BC  
Don't worry  
Doubting HCP abilities  
Emotional duress after told DX  
Emotions encouraged to let it out  
Facing Mortality  
Familiarity to BC aids control  
Fear of leaving family  
Fear of recurrence  
Feel like life matters you sho..  
Feelings that I got from the h..  
Finding benefits of BC  
Follow these guidelines  
Follow-up care gynecologist  
Follow-up care oncologist  
Follow-up care surgeon  
Gap in psychological care dx to survivorship  
Getting drunk and driving  
Getting taken care of while in treatment  
Going back to school  
Had cancer for a long time before found it  
Have a positive attitude  
Have no control over that anyway..  
HCP held accountable for his inadequacies  
HCP actions cause non compliance  
HCP communication  
HCP don't want to know about mental struggles  
HCP giving BCS wrong diagnosis  
HCP Giving Control  
Hcp giving guidance  
HCP not aware of care roadblocks  
HCP reaching out to BCS  
HCP taking away control of seeking assistance  
HCP taking away emotional control  
He misses listening to me.  
Helping others helps emotionally  
Hiding emotions for family  
Humor as a buffer  
I became an activist for them  
I didn't think it was fair  
I didn't think that I deserved..  
I don't feel like my journeys ..  
I feel like there is a greater..  
I have decided this is not goi..  
I helped myself  
I just went through the motion..  
I learned that there was more ..  
I mattered.  
I see my other doctors for my ..  
I still don't know where I am,..

I think he is in a hurry  
 I was angry  
 I was trying to celebrate bein..  
 I will never be perfect.  
 Information causes fear  
 It is my opinion they don't wa..  
 It's gone but it's not  
 It's probably because I pushed..  
 keep my emotions in check and ..  
 lasting physical limitations  
 Listening  
 loss of control not having any control over the disease  
 loss of control of ability to work  
 loss of control of body image  
 loss of control of family roles when ill  
 loss of emotional control  
 loss of emotional control due to meds  
 lost control over my entire li..  
 lost of cognitive control chemo brain  
 lucky  
 mammogram causes fear of recurrence  
 medications causing physical symptoms  
 medications maintenance  
 mental breakdowns  
 My journey through this process..  
 No control over when illness strikes  
 Not feeling different  
 only one in family with BC  
 outcome never going to be the same ever  
 Outcomes educating other BCS  
 Outcomes helping others with Cancer  
 outcomes I know these people  
 outcomes people take for granted  
 outcomes trying to make sense of cancer  
 outcomes trying to prevent recurrence  
 physical symptoms causing fear of recurrence  
 physical symptoms numbness  
 physical symptoms pain  
 physical symptoms scar tissue  
 post op complications  
 Protecting self by compartmentalizing emotions  
 protecting self emotionally  
 questioning why me  
 quitting job  
 remapping  
 reminders  
 Reminders of BC  
 saying things don't mean  
 Seeking comadarie to ease loneliness in experience  
 seeking information from HCP  
 sit and listen to you  
 social support  
 spirituality as a buffer  
 Survivor guilt



symptomatic and not knowing  
take my chances  
Talking.  
The fear of it coming back has..  
The medical people and the res..  
trying to make sense of what i..  
tumor markers cause fear of recurrence  
uncertainty of future  
uncertainty of treatment path  
Unfamiliarity with BC causing fear  
unlucky  
Wanting things to go back to pre BC  
wanting to get away  
what do I my leave my family w..  
Where do we belong  
wonder why something like that..  
you have to completely alter y..  
you have to do what you have t..  
You know, you can get sick and..

### **Appendix K. Narrative Summaries of the Participants**

In this section participants are described to provide a brief narrative sketch of each participant. The participants will be addressed as Subject 1, Subject 2 and so on to maintain anonymity.

The first participant, Subject 1 was a 39 year old female who had finished treatment three months before the interview, for triple negative breast cancer. She is married with a school-age daughter. She stated she had begun to start to move on with life after completing treatment, specifically the last phase of her breast reconstruction. Uncertainty, fear of recurrence and fear of death were voiced as major stressors at this point and cause emotional duress. In response to these stressors Subject 1 stated she was keeping herself self emotionally calm, helping other BCS in order to help herself. Subject 1 stated she was taking control of diet, weight and exercise to prevent recurrence. Additionally to manage the negative feelings, she stated she distracted self with work/family roles and by putting feeling in the back of her head-compartmentalizing emotions. While stuck in a traffic jam on the way home from this interview, I Googled triple-negative breast cancer as I was unfamiliar with this classification. As I read about this type of cancer I felt down as the recurrence can be high for this type.

Subject 2 was 66 years old. It had been 13 year since she completed treatment and she stated she feels emotionally “good”. Subject 2 is divorced, retired and lives alone nearby family. Even though it had been many years she stated: “It’s gone but it’s not!”. This is the first time that the perpetual nature of the survivorship process was talked about. Subject 2 stated she has emotional

distress when goes for mammograms, blood-work or physicals. She also stated 5 year milestones give her relief. She stated she took control of emotions, stating “I decided it is not going to run my life anymore”. Several cutting points were discussed: waiting for diagnosis to be confirmed, after 5 years ( significant to her because of research) and the time when she decided breast cancer was not going to run life 2-4 years after treatment.

Subject 3 was a 49 year old who was 13 years post treatment. She stated her cancer was estrogen positive. At the time of the interview she was struggling with loss of cognitive control from chemo-brain. She also was struggling with finding out “who she is?”. This subject acknowledged the lack of psychological care from HCP. Stating: “ they aren’t concerned what is going on mentally” In response to her concerns this subject was educating self, using complementary treatments, helping others: started support group facilitates group and even wrote a book. She talked about helping others to help self. This theme also was in Subject 1’s interview. She was educating others, formally and informally. Subject 3 talked about acceptance, “ it is what it is” Acceptance was the key to emotional well- being for this subject.

Subject 4 was a 70 year old who had been a survivor for 5 years. She described herself as moving on. Some of the concerns Subject 4 had were doubting HCP and fear of recurrence. She was making social comparisons to a friend that also had breast cancer and in comparison to her friend she stated she felt lucky. When asked what she meant in a follow-up phone call, she stated it meant they caught her cancer early and that she didn’t have to have chemo. The

researcher looked up the definition of luck and it is defined as a good outcome that a person cannot control. In response to her concerns in regards to breast cancer subject 4 stated she had a feeling of acceptance of her diagnosis. Additionally she also was proactive and was educating others, especially her female family members about the benefits of breast cancer screening mammograms.

Subject 5 was an animated 63 year old who was an 8 year survivor of DCIS breast cancer. She stated she continued to have emotional duress over the residual scars and stated she would not recommend the treatment plan she chose. Subject 5 talked about acceptance that cannot control getting cancer. She was bothered by her loss of ability to be employed. She spoke of taking control of care with decisions. She also talked about learning about her body, and learning to listen to warning signs of health care problems. The main concerns of this subject were: body image issues, facing mortality, ongoing physical symptoms and fear of recurrence. In response to these concerns she spoke of avoidance of cancer awareness events but stated she donated in different ways. She spoke about compartmentalizing emotions and keeping emotions to self. She also stated she used prayer-spirituality to cope.

Subject 6 was a 42 year old who had completed treatment 2 years before the interview. While in treatment she completed graduate school. Subject 6 spoke of moving on and accepting loss of control of cancer. Her main concerns were: hiding emotions to save family from distress, doubting competency of HCP as she explained that she had a lump that was felt for 5 years and had negative

mammograms. Subject 6 talked about asking Why me? She spoke of struggling, trying to make sense of why she got breast cancer. She also spoke about accepting that cannot control breast cancer then or in the future. She talked about the fear of recurrence and in response to this she stated “you cannot worry about things you cannot control”. In response to her concerns she said she is taking control of actions and emotions

Subject 7 was a 42 year old mother of 3 daughters. She had found her abnormality while breast feeding her first baby. She had to interrupt her treatment as she became pregnant during treatment. There was a moral to the story for me in this interview as this subject talked about not getting her period and everyone assumed because she had difficulty getting pregnant with her first baby that she couldn't be pregnant. It was alarming to me that no one did a urine pregnancy to check as she was on chemo. Needless to say she was several months pregnant before they ceased the chemotherapy. Subsequently she had a healthy baby, then resumed treatment. She had another child after treatment. This subject also successfully breastfed after her mastectomy and treatment. Subject 7 spoke of accepting loss of control of breast cancer and believing that breast cancer happened for a reason. She stated she found benefits from experience. In response to her concerns she talked about “remapping” her life, compartmentalizing negative feelings and controlling things that she can. She also spoke of balancing the role of being a mother while in treatment and not having time to dwell on issues.

Subject 8 was a spry 81 year old, who was a pleasure to interview. She had completed treatment 24 years ago and then had recurrence 21 years ago, She stated she felt cancer is part of her past. She spoke of reminders: blood work. This was an interesting interview as she spoke about past treatments that caused a great deal of loss of control and fear. She stated when women used to have biopsies it was under general anesthesia and if the surgeon felt they needed to have a mastectomy that a family member would give permission while they were anesthetized. In the case of one of her friends, she woke up with a bilateral mastectomy without any warning. She also talked about breast cancer support groups were discouraged by the physicians. Subject 8 spoke about keeping educated about breast cancer to be able to answer newly diagnosed women's questions if asked. She continues to go to support groups and finds ways to helping support other breast cancer survivors. In response to the negative feelings about breast cancer she stated she accepted the diagnosis, compartmentalized emotions

And took control of actions.

Subject 9 was 59 year old who had completed treatment 7 years ago. Subject 9 spoke about accepting that she cannot control cancer and about compartmentalizing negative feelings. She talked about feeling a hardness inside of her breast and having a negative mammogram. She was then scheduled for a follow up mammogram several months later, but was bothered by the hardness. She talked about taking a non-conventional method of getting a mammogram earlier than scheduled, by going into the imaging center and telling them she was

scheduled. She was given a mammogram and she did indeed have breast cancer. She also spoke at length about the paradoxical modifying effect healthcare providers can have upon psychological well-being. At the time of the interview she was being worked up for possible bone cancer. In response to her diagnosis she stated she tries to help others yet tried to be transparent with her survivorship status. She spoke of reminders: mammograms, blood work causing uncertainty and fear of recurrence. She stated she compartmentalizes negative feelings, uses social support both formal support groups and informal support of friends and family to cope. She states she tries to control her diet and exercise to prevent recurrence. And Subject 9 stated that the familiarity with the breast cancer experience also helps feeling of fear of recurrence as she had been through the process once already.

Subject 10 was a 71 year old who had completed treatment 26 years ago. She spoke of accepting cannot control cancer. She definitely helped others and participated in constant education on breast cancer as she is the facilitator of the local breast cancer survivor support group. She is regarded as the community credible authority. She talked about health care providers giving and taking emotional control. She uses meditation, social support to cope. She talked about taking control of actions and decisions. Subject 10 also stated her controlling things she can: exercise, actions education. She stated humor was her best friend during her experience and was extremely witty and articulate.

She spoke of taking control of emotions whether it is compartmentalizing or accepting no control over cancer. Additionally she spoke of breast cancer survivors seeking social support in camaraderie to ease loneliness in experience.

Subject 11 was referred to the researcher by Subject 9. The researcher was a bit reluctant to do this interview as this woman was 47 year old who had been finished with treatment for 5 years but had recently found out has bone metastasis. What was amazing was this woman's acceptance that she could not control cancer. The interview was not negative but was inspiring as this subject had a strong sense of spirituality and faith in God. Although the cancer was back she continued to live a peaceful life. She drew from spirituality as she had a hard time leaving her home and her only son was incarcerated. Although she did not have frequent contact with social support, she did feel she was supported. Her biggest concern was the feeling that she was going to be alone when she died. She was just starting treatment to control the cancer and was unsure of her prognosis timeframe at the time of the interview. She said that was alright with her as she needed to first process the fact that the cancer had returned. She stated she was not surprised and she felt it would come back anyway.

Subject 12 was scheduled before the researcher went to NYC to meet with Barney Glaser for a troubleshooting seminar. Although after meeting with Dr. Lev and Dr. Glaser it was apparent that the data was saturated, the researcher wanted to do this last interview as Subject 12 had indicated she had experienced breast cancer with recurrence and the researcher also wanted to further theoretically sample.





Subject 12 was a 64 year old who had completed treatment 8 years ago for her initial breast cancer and 5 years ago had a recurrence. The day before the scheduled interview the subject called and cancelled the interview via a voice message citing “had a lot going on”. Later that same day she called again asking if she could still be interviewed. She explained she was in the midst of being worked up for brain cancer and had been having emotional distress. She stated that in-between he calling to cancel and the current phone call she had received the news that she did not have brain cancer and that her MRI results were fine.

Subject 12 talked about her recurrence scare and about accepting cannot control cancer. She was questioning whether she had been compartmentalizing too much of the feelings she had about the diagnosis of breast cancer. She stated she was grateful to speak about the entire past and recent experience with the researcher. In response to her concerns, Subject 12 spoke of using spirituality and social support. She spoke about accepting cannot control cancer and about controlling many different aspects of her life instead. This interview showcased the cyclic aspect of the survivorship process and how after the initial assault of breast cancer how survivors can move quickly through the stages to attain emotional order.

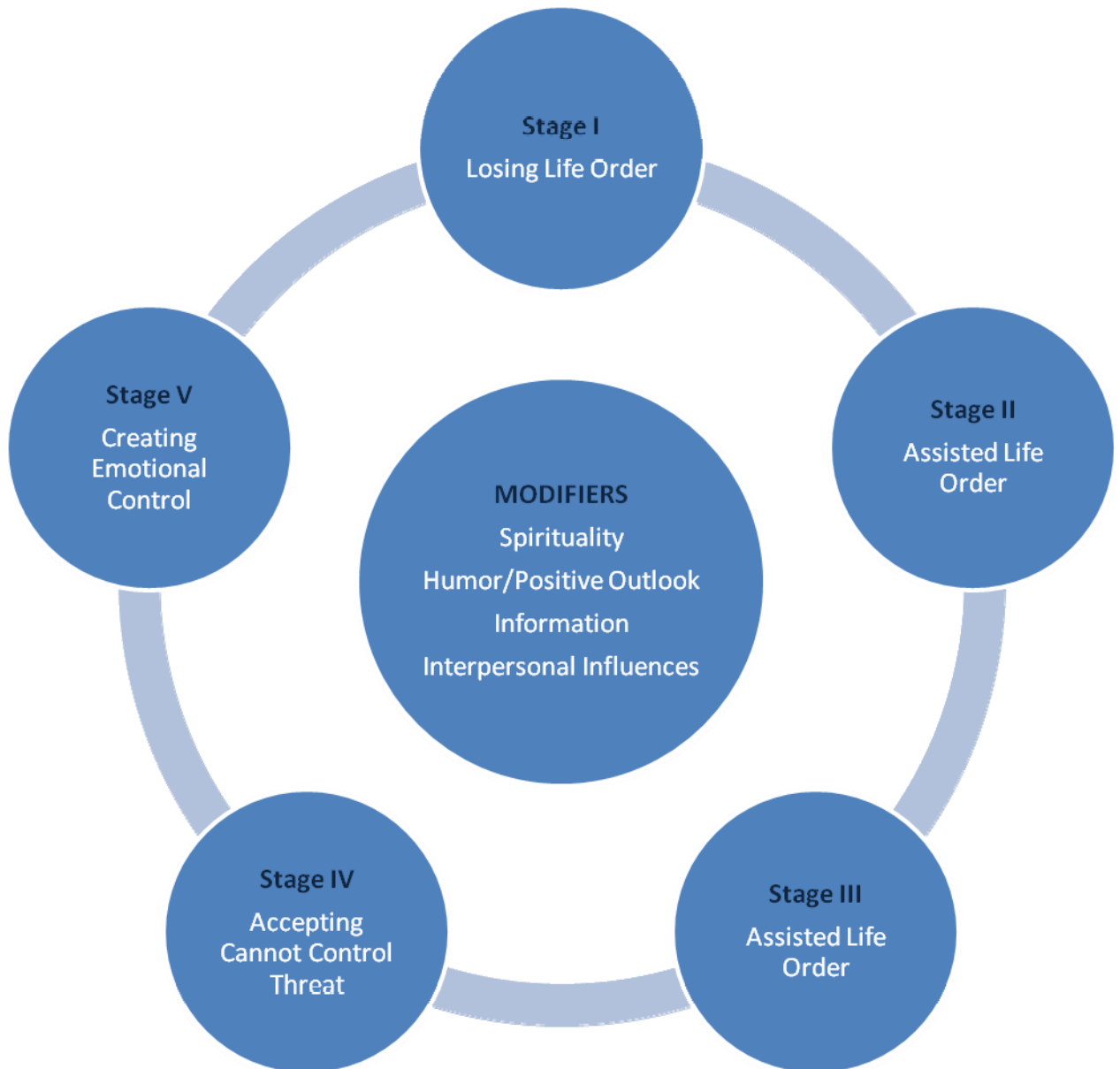
## Appendix L Journal

## INITIAL HYPOTHESIS MODEL WITH LITERATURE REVIEW

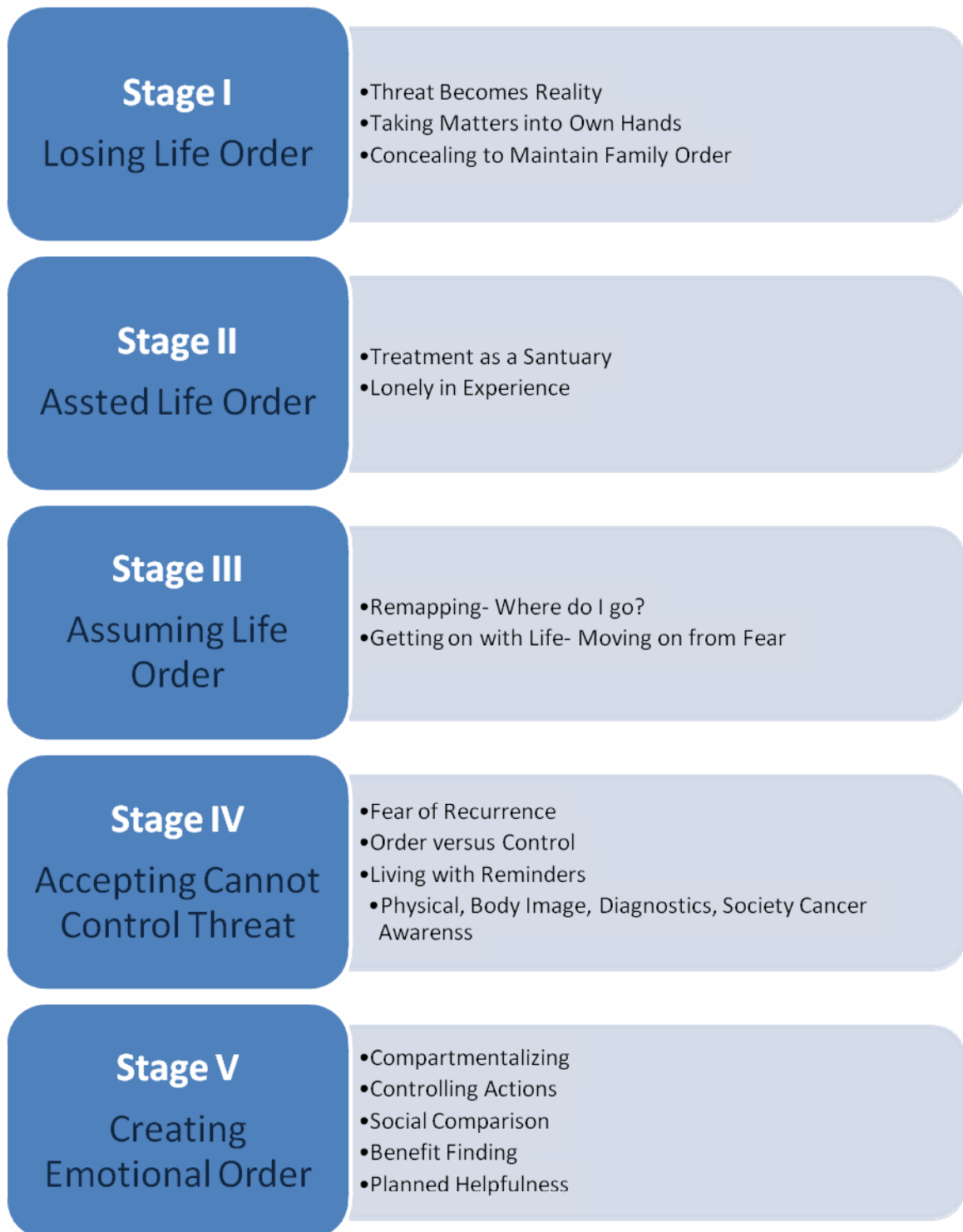
Stages of Survivorship							
NCCS (1985)	Diagnosis Begins the Survivorship Process					Death: Ends the survivor process	
Mullan (1985)		Acute		Extended End of treatment to 5 years	Permanent		
Miller et al.  (2008)				Transitional Survivorship	Maintained Remission		Cancer Free & Free of Cancer
					Cancer Free		Long-term Problems Secondary to Cancer
					Living with Cancer		Second Cancers
Galvan, et al. (2009)		Diagnosis	Treatment	Extended	Permanent Secondary Cancer		
Yingling (2013)				Transitional Survivorship 			

***THE GROUNDED THEORY OF NEGOTIATING EMOTIONAL ORDER***

***Stages with  
Modifiers***



**THE GROUNDED THEORY OF NEGOTIATING EMOTIONAL ORDER**  
***Expansion of Stages***



### Appendix M Sample Characteristics

Subject	Age	Race	Time since end of treatment	Treatment	Breast Cancer Type
1	39	White	3 months	C,R, BM	Triple Neg
2	66	White	13 years	R, L	Unknown
3	49	White	13 years	C,R, L, SM	Estrogen Pos
4	70	White	5 years	M	Unknown
5	63	White	8 years	M	DCIS
6	45	White	2 years	C,R,SM	Unknown
7	42	White	8 years	C,R, SM	Unknown
8	81	White	24 years 21 years	C, R, BM, Recurrence	Unknown
9	59	White	7 years	R, L Being worked up for bone Mets	Unknown
10	71	White	26 years	C, R, SM	Unknown
11	47	White	5 years	C, R, SM Mets	Unknown
12	64	White	8 years 5years	C, R, BM Recurrence	Hormone Neg HER2 Pos

KEY: C-chemotherapy, R-radiation, SM-single mastectomy, BM- bilateral mastectomy, L-lumpectomy, Mets-metastatic

Subject Years After Treatment for Breast Cancer	
0-5	4
6-10	4
11-15	2
16+	2

Subject	Relationship	Employment	Education	Sees PCP	How often see PCP
1	M	FT	HS+3	YES	Q 6mths
2	D	R	HS	YES	Yearly
3	S	FT	HS+4	YES	For sick call only, 2 years after Rx
4	W	FT	HS	YES	Self-labeled: non-compliant
5	M	D	HS	YES	Q 6mths
6	M	FT	HS+6	YES	Yearly after 2 years after Rx
7	M	PT	HS+4	NO	None
8	M	R	HS+6	YES	Yearly
9	D	R	HS+4	YES	Yearly
10	P	R	HS+4	YES	Yearly
11	S	D	GED	YES	Back in Rx
12	W,RM	R	HS+4	YES	Yearly

KEY: M-married, D-divorced, P-partnered, W-widowed, RM-remarried, FT-full time, PT- par time, D-disabled, HS-high school, GED-high school equivalency, Rx-treatment

## Curriculum Vita

**Jennifer Ann Klimek Yingling PhDc, APRN, ANP-BC, FNP-BC**

**January 18, 1973**

**St. Lukes Memorial Hospital Utica, New York**

### Education

**Doctorate**, PhD candidate, currently full time doctoral student at Rutgers University, Doctorate of Philosophy Program focus nursing

**Advanced Certificate**, Family Nurse Practitioner, 2001

State University of New York, Institute of Technology

**Masters**, Adult Nurse Practitioner, 1997

State University of New York, Institute of Technology

**Bachelors**, Nursing, 1995

State University of New York, Institute of Technology

**Associate in Applies Science**, Nursing, 1993

Mohawk Valley Community College

### Experience

2007- Present	SUYIT Nursing Instructor
1997-present	Family Nurse Practitioner, TEAM Health East SEMC Emergency Department 1997-2013 FSLHC Emergency Department 2009- present
1993-Present	Registered Professional Nurse Faxton St. Luke's Healthcare Hospital Supervisor Emergency Room Medical Surgical Nurse Practitioner IRU

### **Professional Activities**

#### **Publications**

2010, Sellers, K., Millenbach, L., Kovach, N. Klimek Yingling, J., The Prevalence of Horizontal Violence in New York Nurses, Journal of New York State Nurses Association, Fall/Winter.

#### **Textbook Reviewer**

2011, Loomis, Griswald, Pastore & L. Dunphy Chapter 18 Psychological Problems in Primary Care: The Art and Science of Advanced Practice Nursing, 3<sup>rd</sup> Edition; F.A.Davis, Approved N.Y.S. Nurse Practitioner Protocol Book