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The Lived Experience of Women with Breast Cancer During the  
Surveillance Phase of Recovery: A Hermeneutic  
Phenomenological Inquiry

Patricia K. Amado

THE LIVED EXPERIENCE OF WOMEN WITH BREAST CANCER DURING THE  
SURVEILLANCE PHASE OF RECOVERY: A HERMENEUTIC  
PHENOMENOLOGICAL INQUIRY

DISSERTATION

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Patricia K. Amado

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## Abstract

**Background:** Breast cancer is one of the most prevalent types of cancer today among women of all ages. Many women are being diagnosed each year and learning to cope with a chronic illness. Accompanying the victory of survivorship, however, are challenges in the surveillance phase of recovery. Surveillance is the time after surgery, chemotherapy and /or radiation is complete and the patient is continues to be receiving regular scheduled check-ups by the oncologist. Breast cancer survivors face many fears during this period of time, including fear of recurrence, loss of health, or fear of dying from the disease to name a few.

**Purpose:** The purpose of this study was to illuminate the lived experience of women after they have undergone their treatment regime for breast cancer and have entered the surveillance phase of recovery. This study gave a voice to the women's experience through their life story and the resiliency they demonstrated while transitioning to a new life within the context of illness.

**Philosophical Underpinnings:** This study was guided by Max van Manen's (1990) hermeneutic phenomenological perspective.

**Methods:** A purposive sample of 13 women ages 25-75 years old from survivorship clinics in south Florida was selected to explore the question: What is the lived experience of women with breast cancer in the surveillance phase of recovery? Data collection was gathered with one-hour semi-structured interviews and was audio- taped, transcribed for verification, and member checked by the researcher. Data analysis included interpretation and description of textual writing guided by van Manen's (1990) six activities of research methodology.

**Results:** The themes that arose from the study were transilience, transition, and acceptance. Liminality was the foundational essence of the themes in this study and was paramount in creating a pathway to moving forward as well as understanding the ambiguity and uncertainty experienced by women affected by breast cancer.

**Conclusion:** This research study exposed the complexities of the health challenges confronting women living with breast cancer while in the surveillance phase of recovery. A significant element of this lived experience was understanding the threshold between wellness and illness which the women unreservedly shared. Gaps in current literature highlight the need for additional research to understand the utility of liminality in all stages in the survivorship trajectory.

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## **DEDICATION**

To my family, words could never express the deep love and unending gratitude I have for you. To my husband, Juan, your love and support are eternal. I could have never done this without you encouraging me on each day. You taught me the true meaning of unconditional love. To my sons, Francis, Johnny, and Jordan, who also showered me with unconditional love and laughter and encouraged me and guided me through the journey with a boundless tenacity and pride for their mom no matter how difficult it became. And lastly to my mother, who gave me the confidence and the love only a mother can give. You are truly my providential angel.



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## CHAPTER ONE

Illness is the night- side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. (Sontag, 1978)

Every human being, during their life, is at risk for experiencing illness. One particular illness that creates heightened fear and anxiety is cancer. According to the American Cancer Society (ACS), 1 out of 8 women will be diagnosed with breast cancer in their lifetime (Dalton, 2005). For women, breast cancer is an increasingly common type of cancer that affects all age groups. According to the National Cancer Institute (NCI), the incidence of breast cancer is increasing, along with survival rates (Ward, 2011). The National Cancer Institute suggests (NCI) reports 12.8% of women will be diagnosed with breast cancer sometime during their lifetime. Estimated rates of the 2.4 million breast cancer survivors in the United States in 2013 were as follows: 232,340 new cases (female); 2,240 (male) : 39,620 (female) deaths; 410 (male) deaths and there are approximately 2.4 million breast cancer survivors in the United States surviving years following diagnosis (Odle, 2011). The need to study this growing population of survivors is crucial to improve how health care professionals understand and treat this illness and improve the quality of the survivor's life. This study, therefore, focused on the course of breast cancer in the surveillance phase of recovery.

The term survivor in this study is defined as a dynamic process for breast cancer patients who have been diagnosed and are dealing with surveillance of the disease for the

rest of their lives. Surveillance becomes a phase where the patient is being watched for any latent effects after acute treatment of surgery, chemotherapy, and/or radiation is complete. The follow – up visits can continue up to five years to monitor any type of recurrence. It is a state of vacillating between illness and wellness in between weeks of continual physician appointments. The appointments are less frequent after acute treatment ends and surveillance begins. Most women are seen every 12 weeks for blood work and every few months or years for body scans depending upon the oncologist's protocol. Surveillance is a constant ebb and flow of emotion for the patient waiting for results.

In selecting a qualitative research design, using a hermeneutic phenomenological approach was chosen to examine the complex and multiple issues surrounding breast cancer in the surveillance phase of recovery. The primary focus of a phenomenological study is to capture the richness in the everyday meanings and routine of the person's life through their personal story. A phenomenological study provides a rich look into self and is well suited for understanding the lived experience of illness (Carel, 2012).

### **Background of the Study**

According to the American Cancer Society, 18 million Americans are projected to be living with cancer by the year 2022. This figure represents a significant increase from the 13.7 million Americans who are living with a history of cancer as of 2012 (Ward, 2012). The National Cancer Institute (NCI) projects that in 2013; approximately 39,520 women of all ages will die of breast cancer. Nonetheless, there is a growing population each year that becomes survivors and live the rest of their lives with the effects of the disease. Breast cancer is second in incidence to lung cancer in the U.S. and 30% of all

new cancer diagnoses are breast cancer (Grant, Economou & Ferrell, 2010). Nevertheless the three most common cancers in women are breast, lung, and colorectal, respectively. The leading cause of cancer deaths among women are lung, breast, and colorectal (Ward, 2012).

Breast cancer impacts many facets of a woman's life such as physical, emotional, as well as spiritual at many different levels and at different times throughout the journey. The normal course of therapy from diagnosis to the last treatment is approximately six months (Stephan, 2010). After that point the patient transitions into the surveillance phase of the treatment plan. After acute treatment is finished, such as surgery, chemotherapy, and/or radiation, which take approximately six months, the patient continues to be monitored. The appointments that were once a week to monitor blood tumor markers are now every 12 to 16 weeks depending upon the prognostic indicators (Stephan, 2010). Some women are monitored differently depending on the initial diagnosis and plan of care. Generally, the routine is continual maintenance throughout the illness/wellness continuum for these patients every three months. The way that women live in the meantime is important in understanding her life in this dynamic state of illness and wellness.

Each woman may differ in regards to individual needs that accompany the health challenges of breast cancer. Public concerns regarding costs of continuing care and possible insurance denials due to latent effects of the initial treatment are some of the few problems in practice that are beginning to be addressed in clinical practice. Survivorship includes issues related to the ability to get latent effects covered by insurance, side



effects, second cancers, and quality of life (Ward, 2012). The issues in the continuum of cancer care are many and may be different for each person at any given time.

Women are living with this disease for years after initial diagnosis and treatment, but little research has assessed the lived experiences of women with breast cancer in the surveillance phase of recovery. Treatment is giving hope to many survivors, but there are few evidence-based studies addressing the post-acute treatment stages of survivorship and subsequent care. It is important to understand the disease as a dynamic state through which one is experiencing illness and wellness sometimes simultaneously. The post-treatment phase brings a redefined state of health. In the advent of physician visits, the patient may feel good physically and emotionally because the disease is under control or not progressing, giving him or her a sense of hope. The disease may have been treated with the standard protocol for breast cancer; however, surveillance is needed for many years post initial treatment. Surveillance is not the same as palliative care in this study. This time of being “watched over” does not necessarily mean the participants are at the end of their lives. Palliative care for the purpose of this study is when the patient is treated for ongoing symptoms from the cancer. The comfort measures are to alleviate complications with palliative care and essentially a time to provide care until the end of life which may be in the near future. The surveillance phase is the time after acute treatment ends and one is monitored more infrequently in comparison to a person at the end of life who may need daily care.

Understanding the trajectory of the disease is vital to improving health outcomes and improves overall quality of life. Surveillance every three to four months is a reminder that the illness must be monitored closely. It may appear the disease is in

remission, meaning it is presently inactive or not progressing and is managed by medication to stop the progression of the disease. The patient may experience a sense of wellness while still under the watchful eye of the oncologist. Even though there is a plethora of research about cures and causes of breast cancer there is a great need to study survivors and health care services throughout survivorship. Unfortunately, breast cancer rates keep increasing in women of all ages at an alarming rate. It is vital for clinicians to be aware of the complexities in the patients living with breast cancer in order to improve the patients' quality of life.

According to a recent research study conducted by Marriotto, Yabroff, Feuer and Brown (2011), projections of costs of survivorship in all cancers continue to grow with an alarming rate of the growth of breast cancer. The study was based on the most recent data available on cancer incidence, survival, and costs of care. In 2010, medical costs associated with cancer were projected to reach \$124.6 billion, with the highest costs associated with breast cancer (\$16.5 billion), followed by colorectal cancer (\$14 billion), lymphoma (\$12 billion), lung cancer (\$12 billion), and prostate cancer (\$12 billion); these figures reflect the economic side of cancer survivorship ( Marriotto et al., 2011 ). With the increase of all cancer survivors due to improved treatment plans and new medication regimes, the need to study survivorship in all types of cancer will continue to grow. Survivorship from many types of cancer is relatively new as a phenomenon, and with new medications and treatment modalities, the population is living longer with this disease (Marriotto et al., 2011).

Amassing research gives an even clearer picture of the care that is needed for cancer survivors such as surveillance programs, education, nutrition, and depression

screenings, among many other problems. More and more people are living post treatment, and recent studies compare different types of follow-up care for survivors, but there is little evidence of high-quality research on the transition from early survivorship to mid, or late survivorship and how to implement models of care across the cancer continuum to accommodate each patient's progress (Ward, 2012). The cancer survivorship movement began in 1986 with the establishment of the National Coalition for Cancer Survivorship (NCCS), and the need for such advocacy at a national level continues to grow. The Institute of Medicine (IOM) published a report in 2006 that pushed the establishment to focus on the patient survivorship clinics in the community (Grant et al., 2010). The need to study this facet of breast cancer may lend multiple ways of improving the needs of cancer survivors into a continuum of care for the remainder of their life. There are projections from various disciplines about the meaning of survivorship but little knowledge significant to the journey and transition after treatment is complete. There is a gap in literature exploring the phenomena of being a survivor and exploring the essence of the actual lived experience of a survivor while living under constant surveillance.

Phenomenology is the study of the life world, the world as we immediately see it pre-reflectively rather than as we conceptualize, categorize, or reflect on it is different from any other approach because it attempts to gain insightful descriptions as an individual experiences the world (van Manen, 1990). During this life-threatening battle, patients may be overwhelmed by both the treatment and transition to becoming a survivor. Research of these specific phenomena may provide innovative and improved

standards of care to help guide and understand the essence of the illness and life world of living with and through the breast cancer experience.

### **Statement of the Problem**

Breast cancer remains the most frequently diagnosed cancer in women compared to all other cancers. Breast cancer is sometimes viewed as a life-threatening disease, but women continue to survive with the advances of preventative measures and treatment. With the increase of incidence of this chronic disease, the mortality rate is on the decline due to screenings, early detection, and adjuvant therapy, meaning there now is an increase of people living with the disease post treatment. Initial treatment may end with chemotherapy or another accepted intervention; nonetheless, breast cancer continues to be a chronic disease, and lifelong surveillance is needed throughout the journey.

The problem lies in understanding what it means to be a breast cancer survivor living under constant surveillance of the disease and trying to stay physically and emotionally sound. Understanding the actual lived experience from this perspective may shed light onto the true essence of what it means to live with this insidious disease throughout the entire journey from diagnosis to a new life post treatment. Findings may impact the health care plan and future interventions during the years involved in the surveillance phase of living with this disease.

### **Purpose of the Study**

The purpose of this phenomenological study was to explore the lived experience of women with breast cancer during the surveillance phase of recovery. This study may seek to give voice and meaning to post treatment breast cancer survivors to articulate their individual experiences with surviving breast cancer in order to provide a rich, thick

description of their experiences. The focus of this research is premised upon the surveillance phase of the breast cancer trajectory post diagnosis, surgery and treatment regardless of remission status and prognosis.

### **Research Question**

This study sought to answer the following research question: “What is the lived experience of women with breast cancer in the surveillance phase of recovery?”

### **Philosophical Underpinnings**

The purpose of this study was to use a qualitative approach to explore the meaning of living with and through the illness of breast cancer. Qualitative research reveals multiple realities held by individuals, perceptivity of phenomena, and different ways of being in the world (Munhall, 2007). The study utilized van Manen’s hermeneutic phenomenological approach to explore the lived experience of women with breast cancer, which focuses on a unique view into each human experience through the examination of language to gain knowledge from textual discourse and reflection (van Manen, 1990). This method is effective for this specific study to allow for interpretation of an individual’s life story through his or her words to explore the meaning of the phenomenon being studied.

Husserl, the founding father of phenomenology, focused on a particular aspect of an experience and challenged subjective consciousness. Husserl believed that objects in the external world exist independently and the information about objects is reliable. He argued that people can be certain about how things appear in or present themselves in their consciousness (Groenewald, 2004). Husserl named his philosophical method as

phenomenology, the science of pure phenomena. On the other hand Heidegger, a disciple of Husserl, respectively explored the “lived world” in terms of existence in an ordinary world (Gadamer, 1976). Hermeneutics from the stance of Martin Heidegger essentially defines phenomenology as an attempt to understand phenomena, through language expressed, and expands on the notion of being and time. Both philosophers define meaning in the experience and intentionality of something, and a critical examination of philosophical theories giving rise to modern thought. This innovative way of thinking created a movement toward a new worldview, a paradigm shift in thought. An examination of life from a semiotic point views any social behavior or practice as a text and as a language that can be interpreted (van Manen, 1990).

Through the use of dialogue there develops a narrative way of knowing constructed through a story of the lived experience where meaning is created (Bruner, 1986). In this specific study, the foundation of phenomenology is to understand the complexity of a chronic health challenge and to make sense of it. The hermeneutic view gives attention to the words which give the meaning from the person’s perspective. The philosophy of reason or logic argues human understanding structures all experiences (Linge, 1976). Inherently by using reason, all humans try to make sense out of everyday happenings. A relevant modern philosophical underpinning, defined by van Manen (1990) describes phenomenology as how an individual orients to lived experience, hermeneutics as how he or she interprets the texts of life, and semiotics as how he or she develops a practical writing or linguistic approach to both methods.

With the combination of hermeneutics and phenomenology, there arises a new paradigm or worldview of hermeneutic phenomenology. According to Creswell (2007),

“a qualitative study is defined as an inquiry process of understanding a social or human problem, based on a complex, holistic picture, formed with words, reporting detailed views of informants and conducted in a natural setting” (Creswell, 2007).

Phenomenology encompasses awareness in perception of the self and an awareness of others, which gives the whole idea of the lived experience its intentionality as mentioned above. Phenomenology allows for describing an experience such as the lived experience of being a breast cancer survivor in the phase of surveillance, and through interpretation of texts one can analyze the spoken and written language to describe their lived experience.

In a hermeneutical and phenomenological study, the operative word in phenomenological research is “describe.” The aim of the researcher is to describe as accurately as possible the phenomenon, refraining from any preconceived notion. “The phenomenologists are concerned with understanding social and psychological phenomena from the perspectives of people involved” (van Manen, 1990). Van Manen (1990) profoundly captured the description of phenomenology to the speaking of language in this approach:

[Phenomenological method] has something to say to us— it is the art of being sensitive to subtle undertones of language, to the way language speaks when it allows the things themselves to speak. An authentic speaker must also be a true listener, able to attune to the deep tonalities of language that normally fall out of our accustomed range of hearing, able to listen to the way the things of the world speak to us (p.111).

This approach of a hermeneutic phenomenological inquiry to understand an

ongoing illness, such as breast cancer, is a complementary method of research to examine the lived experience of another. Lived experience is the starting point and endpoint of phenomenological research. The aim is to transform lived experience into a textual expression of its essence in such a way that the effect of the text is at once a reflexive re-living and a reflective appropriation of something meaningful (van Manen, 1990). Viewed from a phenomenological lens, descriptive dialogue are co-created with the subjects capture the complexity of their reality with an ongoing health challenge. Nursing can gather knowledge for further research using hermeneutics (interpretive phenomenology) utilizing language to understand the essence of the experience from their perspective (Munhall, 2007).

The expansion of phenomenology through hermeneutics allows for a more critical view of a person's life world. Coupled with phenomenology in research, hermeneutics is how people interpret their lives and make meaning of the life experience. Through the use of language itself, language is the only way humans can express how they are bound to the world (Gadamer, 1976). Phenomenology guides this study because it explores the immediate lived experience without a preconceived notion of the phenomena. Hermeneutics takes an interpretive view as mentioned earlier and comes from the ontological lens, "being in the world" (van Manen, 1990). The framework of a hermeneutic phenomenological approach gives depth and breadth, allowing a deeper understanding of an individual's journey through the daily battles with a chronic disease, such as breast cancer. Phenomenology is an appropriate qualitative inquiry method to address meaning of a lived experience. A basic underlying assumption illustrated by Husserl is that one can only know what one experiences (Gadamer, 1976). This type of



inquiry is not premised on facts or empirical data from a health perspective, but it originates from personal description, interpretation, and critical reflection from the individual. Central to this paradigm of choice in qualitative research is the choice of intentionality and caring (van Manen, 1990). The phenomena describing human beings' inner experiences, feelings, values, thoughts, and choices and understanding those tenets are vital in order to relate to another's lived experiences (Farren, 2010). This method guides the person with open discourse in order to gather information and understand their lived experience. It is an ongoing process and allows identifying themes and phrases that are directly related to the experience (Creswell, 2007).

#### **Relationship of the Phenomenological Approach to this Study**

The hermeneutic phenomenological approach allows for reflection and transition in the sense of a textual expression of language (van Manen, 1990). This approach to research captures the essence of the phenomena of the surveillance phase in women living with breast cancer. It lends itself to open dialogue and intentionality to understand the lived experience in a deeper sense. Understanding the tenets of phenomenology are vital to relate to another's lived experience. There are many ways to illuminate or speak of the life worlds; however, according to van Manen (1990), there are four existentials that ground most human life worlds, regardless of person or group's particular personal, social, cultural, or historical situation. van Manen calls the first existential "lived space" or *spatiality*, by which he means the way people experience and know the environments in which they find themselves. The second existential is the "lived body" or *corporeality*, which refers to the ways of lived qualities of human embodiment, for example the way a human experiences the five senses and understands the world and how they unfold in the

lived spaces. The third existential is “lived time” or *temporality*, which locates us time-wise personally, chronologically, and historically in relation to our world and how one experiences time. Most of the time the existentials are happening simultaneously in lived time. Lastly, van Manen’s (1990) fourth existential is “lived others” or *relationality*, which refers to the lived connections we have with other human beings. Life experiences through an intentional dialogue help make sense out of health and illness. Language is pivotal to and shapes the situations in which we find ourselves enmeshed, the events that befall us, the practices we carry out and, through all this, the understanding we are able to reach (Crotty, 1998). The concept of intentionality spans the gamut of examining the world; this method acknowledges personal knowing and a true presence are lived through the dimensions of process, illuminating meaning, and mobilizing transcendence (Parse, 1998). A chronic illness such as breast cancer creates a new, complex world for a woman, and the use of hermeneutics as a type of interpretive phenomenology is a good fit for this specific study.

#### **Significance of the Study**

Quality of life is a multidimensional facet of one’s social, spiritual, physical, and emotional well-being. Through utilizing a hermeneutic phenomenological inquiry, the researcher may be able to gain a better understanding of women with breast cancer after the acute treatment phase has ended specific to this illness. This approach may provide direction for further research and development of interventions specifically designed to facilitate survivorship, thus possibly improving health outcomes for thousands of women.

This type of study will enhance further inquiry into the phenomenon of being a breast cancer survivor and the time when there is a pause within the trajectory of cancer

care. The time of surveillance may be experienced differently for each person and may be seen from a temporal state as waiting in the meantime for results of labs and other prognostic tests. The vital information gathered through the examination of the lived experience through language of another may enable health care professionals to care for this population which continues to grow. Increasing the knowledge base on how to care for these patients may allow nurses to address how survivorship affects women physically, emotionally, spiritually as well as financially in the long run. This knowledge can help women with resolving health challenges for the remainder of their lives.

The study may have multiple benefits to research in various disciplines; however the discipline of nursing may greatly benefit in education, practice, research, and public policy.

### **Significance to Nursing Education**

A nurse has a major responsibility to educate patients. It is vital for nurse educators to teach students about long-term effects of breast cancer. In studying the experience of survivorship, there can be an increased knowledge of the disease and an understanding of differences in recovery for each patient. Research about post treatment in the breast cancer patient may allow for nursing education to gain important knowledge about the cancer care continuum from initial diagnosis, treatment, and the remainder of life. It may provide a navigation plan to inform all practicing nurses, nurse educators, and all other health care practitioners who take care of this specific population.

The idea of a cancer survivorship care plan could be integrated in the core curriculum and enable students to better care for this special population. This component

of cancer care could be incorporated into the community health module and allow for improved learning outcomes related to cancer needs in the community.

### **Significance to Nursing Practice**

Health care providers, especially nurses, are the first line of defense to advocate for patients and genuinely care for women with breast cancer. Nurses have an important emphasis on the medical advice and can have a direct impact on how the patient understands the disease process. Increased knowledge in the clinical arena may allow for a customized plan of care for each woman who is facing a life with breast cancer. The improvements in care could educate all health care practitioners to properly manage a cancer survivor for the remainder of his or her life. Increased awareness of the individual's needs may provide important information for the practitioner's knowledge about the health challenges that a survivor faces and reduce unwarranted fears of the disease. When the patient is under surveillance, the in-between time may not warrant an oncologist appointment for every health issue. A better informed nursing community such as an oncology nurse at an outpatient clinic or a nurse practitioner in the community setting may be better equipped to address latent effects that may otherwise not be recognized. It may allow registered nurses and advanced practice nurses to provide thorough care for those women who are sometimes unable to navigate the complex health care system.

### **Significance to Nursing Research**

Studying the new frontier of survivorship may place greater emphasis on the overall well-being of the breast cancer patient. Nursing research in this arena could add valuable knowledge to existing findings related to the topic. A greater emphasis on the

continuum of care post treatment could allow for further exploration of this growing phenomenon. Most importantly, findings in this study may create new interventions that could improve delivery of care and facilitate transition in the recovery stage of the disease process.

Hopefully this research could improve the way health care providers disseminate education on survivorship care. Moreover, further research on the concept of survivorship within this specific time frame adds to the body of nursing knowledge in this specific research topic.

#### **Significance to Health/Public Policy**

In review of the studies conducted on breast cancer, prevention costs are greatly reduced when the disease is caught early. However, in the overall treatment plan can last a lifetime for some women. Several national action plans about survivorship exist in the public policy domain. The NCI and the Centers for Disease Control and Prevention (CDC) have made efforts to amass information that will improve quality of life for all survivors. With proper surveillance, there can be significant savings in overall health care costs that may last the remainder of life. Battling this disease is not over when treatment stops; each year after treatment, there can be latent effects that warrant interventions. However, these effects may not be covered under the cancer care component of a policy. With a sound program to monitor survivors, the problems may be addressed early to ward off greater care costs. This awareness enhances public policy in health care because it would address secondary cancers, promote a stronger management of the disease, minimize potential distress that accompanies cancer, and provide community-based cancer survivorship clinics (Odle, 2011).

From a nursing perspective, the topic of breast cancer survivorship in the surveillance phase is important to study in all the above mentioned areas of education, practice, research, and policy. The need to investigate this specific phenomenon may further advance the practice of nursing.

### **Scope and Limitations of the Study**

This study focused on breast cancer women who are post treatment and have finished active treatment, surgery, chemotherapy, and/or radiation therapy. These women are now in a surveillance mode of recovery.

Limitations to the study may include general access to the participants and the willingness to tell their story. Additional limitations include the homogeneity of the participants and the fact that the researcher is a novice researcher. The actual transcribing the texts and interpretation of the dialogue may be a limiting factor for dependability and confirmability. Having an audit trail of field notes and journaling may help with the translation of the descriptive language and phrases used by the participant and carefully reviewed to ensure credibility.

An important consideration that may limit findings is stage of the disease and preexisting knowledge of prognostic indicators while participating in the study. There can be embellishment of the illness experiences that may not be accurate due to knowledge deficits about the disease. Most importantly, a limitation to this study may be researcher bias from personal experience and perceptual misinterpretations. It is important that as both the researcher and a survivor, to be aware of any preconceived notions of the illness and bracket so that there are no assumptions about their lived experience. That is where the unique framework of a hermeneutic phenomenological

approach would reduce bias and increase the understanding of the lived experience of the other.

### **Chapter Summary**

This chapter presented an introduction to the study of the phenomenon of survivorship. It described the need for further research to explore women in the post-treatment phase of breast cancer treatment. Much attention is given to prevention and perhaps cures; however, few studies focus on the perception of the illness within the context of survivorship. By exploring the lived experience, women and the health care provider may truly gain insight into the meaning of survivorship while in the surveillance mode of recovery.

## **CHAPTER TWO**

### **REVIEW OF THE LITERATURE**

A search of relevant literature across disciplines was conducted to explore the phenomenon of survivorship in a breast cancer patient post initial treatment, using EBSCO and ProQuest Direct search engines, the following computerized databases were used for this search were Cumulative Index to Nursing and Allied Health Literature (CINAHL), Dissertation Abstracts, Educational Resource Information Center (ERIC), Psycharticles & Psychinfo, Modern Language Association (MLA), in conjunction with the Literature Resource Center. The keywords used in the search were surveillance, survivorship, breast cancer, hermeneutics, phenomenology, language, and lived experience. Citations were limited by language to English and by subject to exploration of the concepts. A limitation was imposed to find literature published since 2006 with classics sought by reviewing citations in the published works. Additionally, eight research studies were reviewed in which the experience of being a breast cancer survivor and the transitional care needed post treatment or surveillance phase of recovery were examined from different perspectives. The literature review will be organized to reflect the historical background of the disease of breast cancer, the treatment, and the overall improvement related to survival.

#### **Historical Context**

Although cancer has been around for thousands of years treatment and surgery for breast cancer came to the forefront in the 1870's. William Halsted created new surgical interventions for women with breast cancer called the mastectomy that made a distinct mark in treating cancer (Mukherje, 2010). However the technical success of surgery was



not the sole predictor of long- term survival and its ability to decrease relapse of the disease, thus the beginning of the concept of cancer survival. Until recently the topic of surveillance and survivorship is fairly new in the literature.

The first review of the topic of cancer survivorship was introduced in the early 80's. The number of cancer survivorship studied has increased in frequency with an observable increase around 1996 ( Harrop, Dean, &Paskett, 2011). The focus of research is changing about breast cancer and the long-term management of the disease. The recent literature is focusing on the survivor, women who have been diagnosed and are living with the disease throughout their lifetime. Lay people and some health care professionals may think the definition of survivorship is being disease free for five years. A clear picture of the definition of a cancer survivor and his or her needs from the time of diagnosis throughout his or her lifetime is being painted, but some health care professionals agree the gap is wide in understanding the delivery of care for these patients (Digiulio, 2012). There is a continual need for surveillance education, stress management, physical activity, and nutrition consultation (Digiulio, 2012). These measures have proven successful and improved outcomes for many. The term survivor is explained and is referred to as an ongoing experience throughout the breast cancer patient's life journey after the initial treatment of surgery, chemotherapy, and/or radiation is complete (Odle, 2011). However, the experience of each woman may be very different as she embarks on the journey of acceptance and assimilating to a chronic disease. For many women who are in the recovery phase there are many different physical and emotional needs that are unknown in order to treat them effectively in post treatment years and to improve quality of life (Ward, 2011). The reason for this research is to

explore the essence of the illness through the journey of survivorship in the surveillance phase in order to find ways to improve practice and quality of life in the continuum of breast cancer care.

### **Breast Cancer Trajectory: Diagnosis and Treatment**

The normal progression of breast cancer is important in understanding the complexity of each woman's prognosis. Regardless of the stage of cancer, each woman is faced with her own individual journey with this chronic illness. In the transition to survivorship, the needs are different for each individual depending on the prognostic indicators. Five-year survival rate is defined as the percentage of women with breast cancer who are still living within a five-year period since the original diagnosis. This definition also includes breast cancer survivors who die from unrelated causes (Curran, 2012). Each survivor has a treatment plan regardless of stage at the time of diagnosis. It is vital to understand the disease and the medical treatment a patient must go through in order to understand the lived experience post treatment. This post treatment period involves waiting and may entail obtaining tumor marker counts every 12 weeks or medication efficacy to ward off any cancer progression. This time frame of waiting for results constitutes a constant flow between the illness and wellness continuum. Most women who are post treatment have a specific diagnostic regime depending upon the type and stage of breast cancer.

Depending upon the stage of breast cancer, the usual regime after diagnosis may be a conservative lumpectomy or mastectomy or radical mastectomy followed by six to eight consecutive weeks of intense chemotherapy and/ or radiation if elected by both the

physician and the patient. When women are first diagnosed, the treatment is based on the prognostic and predictive factors (histology, pathology, clinical characteristics, and hormone receptors), with some treatments being more aggressive than others (Tiezzi, Andrade, Marana, Gerieiri, & Philbert, 2009). Thus, to understand the disease, it is important to know the stages of the disease along with prospective survival rates within the breast cancer trajectory. It is also important to understand tumor types to make treatment decisions.

The characteristics of a tumor have better prognostic indicators and are more favorable in treating and surviving the disease (Cianfrocca & Goldstein, 2004). The staging of breast cancer ranges from 0- IV (0 is less life threatening than stage IV). The survival rates demonstrate possible cure of 100% (Stage 0-I), 98% (Stage II), 86% (Stage III), 57%, and (Stage IV), 20%. The current five-year survival rate for localized breast cancer is approximately 94% with no lymph invasion. Once there is nodal involvement, the odds of survival decrease to 84% (Tiezzi et al., 2009). The five-year survival rate is also the relative cancer survival rate, and it is the proportion of patients surviving cancer five years after diagnosis (Dalton, 2005). Each patient has his or her cancer care regime depending upon the stage of the cancer. The course for early stage breast cancer, stages 0, I, and II may differ from a more advanced diagnosis of stages III and IV.

Prognostic indicators can help treat the cancer; however, the need for understanding the transition and resolution in the post-treatment phase of the disease is missing in practice. Survivorship does not start after the five-year mark; that is simply a prognostic measurement for people living with the disease. As soon as the acute

treatments are completed, each patient is placed on a standard protocol of surveillance for as long as the oncologist deems necessary. There are many complex issues in the surveillance phase of recovery that are still unanswered. Much of the literature addresses the biomedical view, which is important, yet the studies define survivors as a group populace and not from a compassionate, humanistic stance.

In the surveillance phase, most women are on an oral anti-cancer drug to ward off any local or regional recurrence. A study conducted by Breckenridge, Bruns, Todd, and Feuerstein (2010) analyzed cognitive limitations in 113 breast cancer survivors after two and three years post treatment and to see what effects it has on productivity not only in patients' personal lives but in the workplace as well. The design was a quantitative perspective using a correlational self-report design to examine cognition limitations after treatment with medication with surgeries, chemotherapy, and/or radiation while being under surveillance of an oncologist. The findings reported a positive association with self-report of cognitive limitations and productivity after a few years post cancer treatments.

Many of the studies that are researching survivorship address topics that weigh the heaviest and need to be addressed such as the latent effects of hormonal treatment, cognitive changes, and educational need regarding emotional support during the transition to the new normal (Klemp, Frazier, Glennon, Truneck, & Irwin, 2011). Adjuvant therapy is part of the trajectory; nonetheless, some women stay the course and face survival issues alone. The exploration into the life world of a survivor may be rich with insightful meanings about the course of their illness and the choices she makes in their health decisions.

A phenomenological study by Stoval (2012) utilizing a selective sample of 100 survivors post treatment explored the expectations of breast cancer survivors and the psychological aspects affecting the illness and living with the disease. The findings demonstrated that there appears to be poor self-reported knowledge from the oncology nurses about caring for breast cancer patients and the breast cancer survivor's needs across the practice continuum. The patient is under strict surveillance, which includes tumor markers every 12 weeks and oral chemotherapeutic agents such as Tamoxifen or Herceptin, depending upon prognostic indicators (Stoval, 2012). Even though *breast* cancer appears to be managed after initial treatment, there are health challenges that women may face that are unaddressed at the clinical level. The findings revealed medical management is not a golden seal on the chance for recurrence or latent complications; it simply is a clinical intervention in the journey to survivorship (Stoval, 2012). Increasing duration of adjuvant therapy improves survival in women with breast cancer, but the impact of adherence to an individual survivor on mortality is unclear. Many survivors choose different paths when it relates to post-treatment decisions given the fact that no one may be helping them navigate the health care system while in the surveillance phase.

Another recent study investigated whether women prescribed Tamoxifen after surgery for breast cancer adhered to their prescription and whether adherence influenced survival (Stoval, 2012). A retrospective cohort study of all women with incident breast cancer between 1993 and 2002 in Scotland was linked to encased prescription records to calculate adherence to Tamoxifen. Survival analysis was the study cohort with 1,633 (79%). The median duration of use was 2.42 years interquartile range (IQR = 1.04-4.89 yrs). Longer duration was associated with better survival but this varied over time. The

hazard ratio (HR) for mortality in relation to duration at 2.4 years was .085, 95% CI =0.83-0.87. Median adherence to Tamoxifen was 93% (Range = 84-100%). Adherence is < than 80% is associated with poor survival, hazard ration 1.10, 95% CI = 1.001-1.21. Persistence with Tamoxifen was modest with only 49% of those who followed up for 5 years or more continuing therapy for 5 years. Increased duration of Tamoxifen reduces the risk of death, although 1 in 2 women do not complete the recommended course of treatment (McCowan et al., 2008). This examination of medical adherence in breast cancer patients is another aspect that requires further inquiry about the psychological and emotional experiences of women who may not have guidance through the surveillance phase and may give up treatment, thus increasing the chances of recurrence. In review of the literature, there is a need for continual monitoring for all stages of breast cancer in women and navigation of the personal regime that is designated for their prognosis.

### **Surveillance and Survival**

In the past, the term survivor was assigned to women who were disease-free for five years (Odle, 2011). Today, the definition is more dynamic to accommodate anyone diagnosed until death, including those who are living asymptotically or with recurrence, even though not all women feel like survivors post treatment (Odle, 2011). The emphasis is on surveillance and transitioning to a recovery period that vacillates between wellness and illness. In essence, the way a human being views the term survivor refers to a dynamic process through wellness and illness as a person faces the everyday challenges of coping with this illness.

The definition for survivor from the National Cancer Institute (NCI) is a person who is from the time of diagnosed with cancer and lives with the disease throughout the remainder of life. However, this study addressed the individual experiencing the disease while in the surveillance phase of recovering and living with the disease. The American Society of Clinical Oncology (ASCO) states that breast cancer survivorship is more dynamic to accommodate anyone who is diagnosed with the disease until death, including those who are living symptom free or with recurrence, even though some women are not comfortable with the term immediately post-treatment (Odle, 2011).

A study done by Documet, Trauth, Key, Flatt, and Jernigan (2012) explored how women diagnosed with breast cancer defined themselves as survivors and when diagnosis occurred. The design was an exploratory, qualitative approach of 112 women who had various stages of breast cancer. Participants were recruited from cancer clinics and interviewed with open-ended questions over the phone using thematic analysis. The findings reported themes such as meaning of survivorship, the defining moment, and the benefits from surviving breast cancer. The prior study postulated that becoming a survivor is an active process and lasts throughout one's life. The study also concluded the need for support after treatment and during follow-up care visits when the patient is under constant surveillance. Surveillance being the time after surgery, chemotherapy and radiation is complete and the patient is under the watchful eye of the oncologist for five years.

Another study that addressed the needs of survivors was done by Burke and Sabiston (2012); its focus was on the importance of understanding survivorship within the context of psychosocial support. It explored the lived experience with a focus on the

importance of physical activity. The study utilized an ethnographic case study approach and included three participants. It was a case study done as a cross-case analysis to emphasize themes in survivors' growth from their adversity. The study explored the post-traumatic growth in survivors' needs as it relates to the body and physical activity. The results of this case study revealed that participating in a physical activity such as mountain climbing provided an opportunity to nurture life priorities, foster self-belief, and cultivate connections (Burke & Sabiston, 2012). The study addressed the lived experience with a focus on importance of support and physical activity to make it through a life-altering event. The study addressed the importance of physical activity and social support while facing breast cancer.

Stages and/or remission status of the disease does not affect the definition of what it is to be a cancer survivor. A recent study by American Society of Oncologists (ASCO) (2011) reported a need for recognition of survivor care plans well after the primary treatment is done. This study retrospectively followed 68 breast cancer patients with early stages of the disease and calculated post-treatment surveillance needs. Until recently, follow-up for survivors have only focused on surveillance of recurrence, but many go beyond that and have left out important other factors (Ode, 2011). The findings of the study simply reflected the need to consider long-term care plans into the post-treatment phase and the importance to keep a tight surveillance on the survivor to improve health outcomes and quality of life.

A study done by Charalambous, Papadopoulos, and Beadsmoore (2009) investigated the quality of care and the effects on improved quality of life. The study included 25 cancer patients, 6 patient advocates, and 20 oncology nurses. The study was



a hermeneutic phenomenological based on Paul Ricoeur's (1981) ideas on the lived experience. The findings were regarded as a theory of quality in cancer care. Based on the approach, the narratives reflected six attributes: a) being valued, b) being respected, c) being cared for and supported, d) being confirmed, e) being cared for religiously and spiritually, and f) belonging. The study's approach was innovative however; it was a descriptive theory of quality of care and demonstrated the schism between empirical data and understanding. Many of the studies lack the depth of examining the life world and lived experience within the context of illness. The lived experience is as individual as a patient's treatment. Throughout the survivorship trajectory, issues related to well-being and quality of life persists. Even with profound problems, each survivor expresses the needs for growth and change, which may contribute to a theoretically based understanding of quality of life in breast cancer survivors (Farren, 2010). Now breast cancer can be viewed as less of a death sentence and more of a chronic illness that is closely monitored.

In summation, whether a woman chooses a lumpectomy or mastectomy, there is now a surge to learn more of the women who are living with this disease and improve the knowledge based on survivorship needs after treatment (Dalton, 2012). Literature speaks of prevention and cures, but those in health care know that simplifies the truth about cancer. Perhaps because the focus has rested so heavily upon preventing, detecting, and treating breast cancer, the pendulum is now swinging to focus on what it means to be a survivor (Odle, 2011). Those studies are vital to possible eradication of this disease, but at the present time, there must be focus on the consequences after treatment (Curran, 2012). The American Society of Oncologists (ASCO) is focusing on awareness and

prevention; nevertheless, more research grant money is now being awarded to survivorship issues. Even with the advent of improved screenings and treatment, this disease is not going away anytime soon.

There is no standard to follow in survivorship and no defined stages or phases have been revealed, only assumptions made by health care professionals as well as lay persons. These assumptions leave a void for research to fill. This study may fill the gap in the exploration into a deeper understanding of this human phenomenon.

Facing breast cancer is an ongoing, dynamic state for a woman. Breast cancer patients may be uncertain and should have a post-treatment plan or guidelines to follow in order to reduce fears about all latent effects of initial treatment. Each woman experiences the illness in different ways. It is important to understand the individual's perception of the phase of survivorship. To find meaning is a philosophical notion, but it helps with transcending disease such as breast cancer and perhaps even death. Women journey toward self-transcendence and quality of life, which may contribute to unitary practice and human betterment (Farren, 2010). With more women at all ages becoming survivors, it is essential to learn more about this part of the journey to improve upon the treatment and quality of life. The gap in the literature is that studies are lacking describing living with illness and the actual meaning of the experience within the life world of a survivor while under constant surveillance by the oncologist.

The aim of many studies still continues to be on the quality of life within the context of the disease. In the literature, disconnect is seen between the oncologists and the primary care physicians and survivorship along with subsequent needs (Stoval, 2012).

That is a clear indication that survivorship within the phase of surveillance and recovery need further exploration in order to improve health outcomes for all.

### **Experiential Context**

My personal knowledge about breast cancer is an advantage as well as a disadvantage. I have been a survivor for five years and have firsthand knowledge of what it is to be a survivor. I am presently in remission but I think about it every single day. It has changed who I am forever. I am familiar with the cancer trajectory as a patient as well as a health care professional. I also have my own lived experience and interpretation of the life world within the context of accepting and living through my illness. I have vacillated back and forth on the true essence of the meaning of illness and the importance of restoring harmony to life. I have also been involved with support groups and have had discourse with many survivors on a casual level. However, I still find it amazing that each woman has her own perception on what illness is and what it means to be under surveillance until the next round of required appointments. Each woman makes sense of the illness in different yet familiar ways. Discovering the true essence of the lived experience is exploring the phenomena from a more human/ontological stance rather than a medical model. Sometimes there is a personal depth somehow acquired when faced with a life-altering diagnosis. There are common threads in each human's life experiences, yet every person may have a different perspective on the actual experience after the fact. It is human nature to want to make sense out of tragedy or ill fortune.

From the researcher's point of view, a hermeneutic phenomenological study explores the lived experience through a collaborative technique with each survivor. It shed light on the need for incorporating the aesthetic side of each woman's journey

regarding how her story relates to her illness and the new life story that may be emerging. Too often, researchers discover while transcribing that putting aside assumptions is easier than getting the actual account from the participant (Fischer, 2009). The view from a phenomenological approach is to discover the life worlds of each survivor.

van Manen (1990) described how Husserl advocated that the researcher brackets away any information that could influence the outcome of the study, which allows for phenomenological reduction to discover essences of the lived world, whereas Heidegger's method allows an individual's life experiences to contribute to the study. By utilizing a method proposed by van Manen, phenomenology is a sober reflection on the lived experience of seeing meaning or "in-seeing" into the heart of things. In seeing takes place in a thoughtful relation to our everyday being involved with the things of the world. A phenomenology that is sensitive to the life world explores how our everyday involvements with our world are enriched by knowing as in-being with another (van Manen, 1990).

Regarding reflexivity, it was imperative to be consciously aware of where I am in the journey as a current breast cancer survivor. Being aware of my personal opinions and my preconceived notions of the disease helped reduce biases to ensure for open dialogue. I also used an aesthetic outlet of music and writing poetry to suspend any pre-assumptions. As the researcher utilizing a hermeneutic phenomenological lens, I am also an instrument in this study due to self-exploration of the phenomenon. It was imperative to keep a reflective journal so I can address my preconceived ideas and assumptions about the journey of cancer recovery. It is a connectedness that may allow the participant to have a human connection because I have lived through the struggle against the illness.

From a reflexive stance, it was important to interpret the language of the participants in the study without forming preconceived notions that may be assumed but not relevant to the participant's story. Bracketing by use of deduction through a phenomenological approach is vital in overcoming one's subjective feelings, preferences, and expectations that would prevent coming to terms with an experience as it is lived through (van Manen, 1990). It was important to interpret each narrative as a brand new lived experience so that the participant's essence of the experience is heard and understood without interjecting my personal lived experiences.

### **Chapter Summary**

This chapter provided an overview of literature reviewed regarding breast cancer trajectory and surveillance during survivorship post initial. The literature supports the need for further exploration into the phenomenon of survivorship in this specific time frame from post diagnosis through treatment and recovery. The literature revealed a need for ongoing evaluation needed in the breast cancer survivor while under surveillance in the continuum of care. By exploration of the phenomena, health care providers as well as the survivor will have an increased awareness of the experiences that women face battling this disease. An increased understanding of the trajectory of survivorship may contribute to improved quality of life while living with cancer.

## **CHAPTER THREE**

### **METHODS**

The purpose of this qualitative research was to explore the meaning of a person's lived experience of the journey through breast cancer. The goal was to come to understand the phenomenon of being a breast cancer survivor after initial treatment is over and a patient enters a surveillance mode of recovery. Examining the interpretation of illness through language explored the experience as it was lived. This study sought to give a voice to the post treatment breast cancer survivors to articulate their individual experiences with surviving breast cancer and provide a rich description of their personal lived experiences.

#### **Research Design**

The use of a qualitative design with a hermeneutic phenomenological approach was followed to study the lived experience of women living with breast cancer. The study utilized van Manen's hermeneutic phenomenological approach in exploring the lived experience, which focuses on a unique view into each human experience through the examination of language to gain knowledge from textual discourse and reflection and conversational interviews (van Manen, 1990). van Manen's six research activities guided the interpretation of the findings. Qualitative researchers postulate that research cannot be seen objectively from the outside. It must be observed from the inside through the experience of the people (Crotty, 1998). Interviews were face to face, audiotaped, and lasting approximately one hour. This method is appropriate for this specific study to allow for interpretation of another's lived experience of survivorship and to understand the essence of the phenomena through language since it is a universal way to express

meaning. The research design followed the suggestion of van Manen (1990) to describe their experience as lived.

The goal in this approach is to explore the woman's experience of what living with breast cancer is in the realm of survivorship in her own words, including the time in-between being sick and being well and the time of constant watchfulness under the guise of an oncologist. The major characteristics of qualitative research are that it occurs in the natural or real-world setting, the emergent design allows for flexibility, and the sample has to be purposeful (Crotty, 1998). The researcher was able to gain insight through listening and reviewing the text to make sense out of their personal descriptions. Stories are people's constructions and perceptions of events, and as such, become a window into how people understand and make sense of what is happening (Clandinin & Connelly, 2000).

van Manen's (1990) approach describes human – science as a blend of hermeneutics and phenomena which explains human existence as one knows it. Figure 1 demonstrates van Manen's practice of reflective writing and interpretation of the texts for exploration of the narrative story. Each of these dimensions is interconnected as depicted in the overlapping of the circles. The interconnectedness of how the stories are told in the narrative and the interpretation of the texts helps to illuminate emerging themes and explores the phenomenon at a deeper level.

### **Language**

The subtle undertones of language through words, stories, expressions and even silence allow the things themselves to speak. This part of the approach is where an authentic speaker must also be a true listener, and be able to listen to the way the world

speaks to us (van Manen, 1990). Listening allows the words of the other to be expressed within the context of the illness. The actual dialogue and the words spoken by the other allowed the researcher to enter their world. It is in the actual telling of the story where the participant's memory of their lived experience unfolds.

### **Hermeneutics**

According to van Manen (1990), reflective writing also referred to as textual practice examines language as a human science based research which may lead to interpretation of what is in the narrative. Constant reflection of the narrative gives rise to repetitive words and phrases, allowing for the emergence of the meaning of the phenomenon through reflection of the thematic descriptions that the participants share.

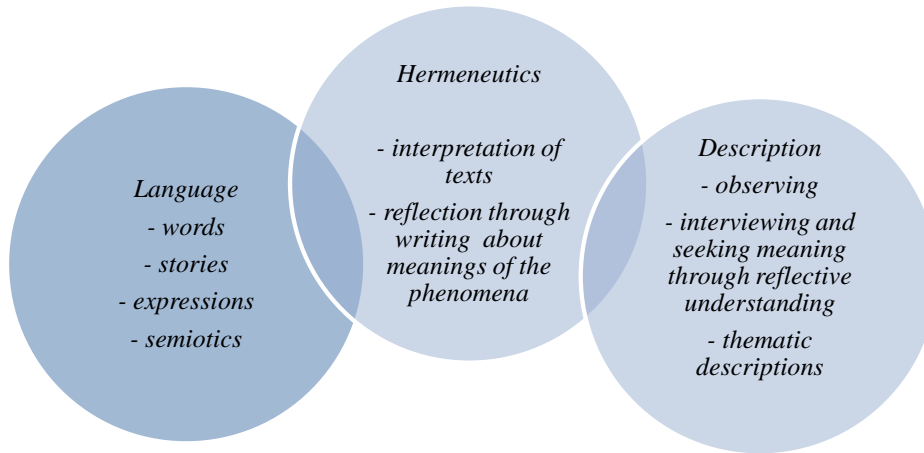
### **Descriptive**

van Manen (1990), concurs this methodology wants to be attentive to how things appear which manifests in the interpretation of texts. Moreover even the facts of lived experience need to be captured. Human science research is the activity of explicating meaning. In order to understand the language in the participant's stories the writing of the next must be closely examined to ensure the meanings of the phenomena is clearly understood. Language through the stories and the interpretation of the texts lead to seeking thematic nuances that help create thematic descriptives that are repetitive in each conversation.

The following figure demonstrates the fluidity that hermeneutics, interpretation and description of the lived experience of the participants in this particular point in time.



THE LIVED EXPERIENCE: EXPLORING THE ESSENCE OF THE LIVED  
EXPERIENCE THROUGH HERMENEUTIC PHENOMENOLOGY



*Figure 1.* A hermeneutic phenomenological approach: Hermeneutics, language, interpretation and description. Adapted by Amado (2015) from van Manen (1990, pp. 2-10).

### **Sampling and Setting**

A purposive sample up to 15-20 participants was sought or until saturation was reached. Sampling was done in the local community. Some participants were from breast cancer survivorship groups, as well as snowball sampling and word of mouth in the community. The study sample consisted of participants who have completed treatment which may be surgery, chemotherapy, and/or radiation for their breast cancer. Each participant was informed of the type of study and be told how the research would be conducted. Each participant was asked by the researcher by telephone to participate in the

study and inclusion criteria was checked at the initial meeting and full disclosure with IRB consent (Appendix A) was addressed. Participants' transcripts were confidential, and they were told that they can withdraw without consequence at any time. In order to obtain saturation in this method, the researcher needed approximately 15-20 participants or until information becomes repetitive and nothing more can be learned from the participant (Munhall, 2007).

### **Access and Recruitment**

A letter of access was sent to the director at the various facilities if requested to perform interviews for the study. A request to place flyers in the common areas was obtained (see recruitment flyer). The flyer contained the title of the study, the inclusion criteria and the need for an informed consent by each participant, and the researcher's contact information.

The recruitment of participants focused on the women willing to volunteer to share their experiences about what it is like to be finished with treatment but still under the watchful eye of the oncologist. The distinction of surveillance compared to palliative care is the continual regular check-ups are the focus of surveillance who have completed curative treatment and have transitioned to a maintenance phase. Surveillance is an active observation phase and not to be confused with palliative care which focuses on symptom management of and late effects of a disease (McCabe et al., 2013). Palliative care is care given to improve the quality of life of patients who have a serious or life-threatening disease, such as cancer. The goal of palliative care is to prevent or treat, as early as possible, the symptoms and side effects of the disease and its treatment, in addition to the related psychological, social, and spiritual problems. The goal is not to cure. Palliative

care is also called comfort care, and symptom management (McCabe, et. al., 2013). A small sample with this method allows for greater detail in the gathering of personal experiences of their illness. Snowballing from fellow participants was welcome as a sampling method as well. The recruitment and the description of the study were reviewed by the researcher as well as the health care professionals at the survivorship clinics when the participant agrees to be a part of the study. The women were identified by the inclusion criteria stated.

### **Procedure**

Using an interactive form of communication through open-ended interviews and open dialogue (conversational interviews) allowed the participants to verbalize their past, present, and future life world as it pertains to their cancer journey. A letter to refer participants by using a thematic approach to categorize essences of the lived experiences, the researcher may understand and arrive at an appropriate interpretation of the essence of the phenomena being studied (van Manen, 1990). The researcher's transcribed interview audiotapes allowed time for immersion, reading and re-reading the texts. This review of the transcripts allowed time to review similarities and differences within the context of the illness during the surveillance phase.

### **Inclusion Criteria**

Inclusion criteria consisted of the following: (a) the women were between the ages of 25- 75 years of age, (b) the stage of breast cancer upon diagnosis was self-reported, (c) able to speak, read, and write English, and (d) are finished with acute treatment and in the surveillance phase of recovery.

### **Exclusion Criteria**

The exclusion criteria would be (a) prior metastasis in recent past from another type of cancer, (b) pregnancy, (c) prior chemo or hormone therapy in the past for a different type of cancer, and (d) under 25 or over 75 years of age.

### **Ethical Considerations/Protection of Human Subjects**

To protect human subjects, the researcher obtained Barry University Institutional Review Board (IRB) approval prior to conducting the study (Appendix A). All procedures were explained to the participants as to the methods of the individual interviews and the transcription of texts after in-depth collaboration with the participant. Before initiating the study, the informed consent was explained to all participants, and all questions pertaining to the study were answered (Appendix B). To ensure confidentiality, all subjects were protected by allowing them to select a pseudonym to protect their privacy. There was minimal risk or benefit to the participants. However, it is possible that talking about their illness may conjure up unpleasant thoughts. According to van Manen (1990), participants may feel mixed emotions as the dialogue ensues. Participants may have increased anxiety, fear, and guilt; nevertheless they may also feel hope, closure, insight, and a sense of awareness of life (van Manen, 1990). Procedures and description of the study were explained to participants in the IRB document, and each subject was given a copy of the informed consent (Appendix B). Counseling services are provided free of service on the premises of the survivorship clinics (list in appendices) if needed. The data were kept in a locked file cabinet in the researcher's home office and also was kept as a secured, password-sensitive file on the hard drive of the researcher's home desk top computer as well as the researcher's personal laptop computer.

Participation in the study is on a volunteer basis. The participants were told they can withdraw from the study without consequence at any time. Audiotapes were destroyed directly after member checking was complete. All other data collected will be kept for 5 years and then destroyed.

### **Data Collection**

Upon approval from the IRB of Barry University; the procedure began. The posting of the flyers to recruit a purposive sample of approximately 15-20 participants were placed in the common areas of the clinic and in the community, such as support groups, doctors' offices, church bulletin boards, and breast cancer fund raiser events. When the participant contacted the researcher by phone through the number provided on the flyer the researcher: a) reviewed the purpose of the study b) reviewed the inclusion and exclusion criteria c) described the time commitment and process of informed consent, and d) determined a mutually agreed upon place and time to meet which will afford privacy to conduct the initial interview.

The researcher performed semi-structured audiotaped interviews lasting approximately one hour. The interviews took place in a mutually agreed upon place by the researcher and participant to ensure privacy. The natural settings allowed for a more fluid and open dialogue. After explaining the purpose, risks and benefits of the study, and the length of the interview, the researcher asked participants if they have any questions or concerns. All questions and concerns were addressed prior to signing informed consent. A researcher constructed demographic (demographic questionnaire in Appendix G).

The participants were asked to choose a pseudonym for the interview to ensure anonymity. The participants were informed of study procedure: (a) The interview lasted approximately one hour and were audiotaped and a second interview for verification within a week was required. This second interview would be by telephone, email or in person to review transcript. (b) They can withdraw from the study without consequence at any given time and if so none of the acquired information would be used. (c) They may refuse to answer any question posed and to stop recorder at any time throughout interview. The researcher requested permission to start the audio recorder at interview to ensure verbatim transcription. The researcher used two audio taping devices to in case of malfunction of a device. The overarching question is: What is the lived experience of women with breast cancer in the surveillance phase of recovery? The researcher used open-ended questions (see Appendix F) to acquire in depth information and enable the clarification of meaning from the participant's responses. After the questions are addressed the researcher asked if the participant would like to discuss anything else. The researcher then concluded interview, thank the participant and make arrangements for the follow up interview within the next week.

The participant was assured that he or she would be able to contact the researcher by telephone or email if they have the need. The researcher informed the participant of the follow-up interview for clarification and the lesser time constraint it will have from initial interview. The researcher kept a journal to allow for self-reflection to reduce bias and personal assumptions of the topic. Also the researcher recorded field notes directly after interview to express non- verbal as well as verbal communication, body language of the participant and the researcher's own personal reflection of the interview process. The

interview was then transcribed by the researcher which meant there was an actual text of the interview. After the interview, transcription, and the initial data analysis, the participant was contacted by telephone, in person, or email to verify transcript to ensure accuracy. Van Manen's (1990) six research activities guided the interpretation of the findings. The major characteristics of qualitative research are that it occurs in the natural or real-world setting, the emergent design allows for flexibility, and the sample has to be purposeful (Crotty, 1998). The researcher was able to gain insight through listening and reviewing the text to make sense out of their personal descriptions. The ongoing evaluation of the narrative is vital to continue to obtain thematic nuances for the final evaluation of the texts.

### **Interview Questions**

The questions may develop as mentioned due to the exploratory characteristics of a phenomenological inquiry; however, there was an initial guiding question in order to promote communication (Appendix F).

The purpose of the leading open-ended question is to create meaning in the realm of surviving and illness. It created the texture of the interview to enhance the initiation of dialogue. The initial question can open up dialogue; however, it is important in phenomenology to let the other's language speak about the experience without interjection so that a preconceived notion of the lived experience is removed. The first question was open ended to enhance the flow of dialogue. What is the lived experience of breast cancer in the surveillance phase of recovery?

### **Demographics**

The data included the ages of the women between 25 to 75 years of age in order to reflect a variety in ages. Participants must speak and write English. Other demographics may include age, educational background, marital status, children, occupation, insurance status, and age upon initial diagnosis. The demographic sheet may be found in Appendix G. This demographics provided a description of the sample characteristics which may be a valuable source of data collection for this specific population being studied.

The comprehensive demographics may allow for greater insight into the participant's life and hopefully lend to transferability of the study for further research.

### **Data Analysis**

The data were interpreted by searching for the themes and sub-themes from the design method mentioned above. Each theme was rated in the transcripts to analyze themes and meaning through each step of their interview. Interpretation of the data aimed at the experience of breast cancer through the constructed story or the actual elaboration of the illness itself. In creating narrative themes, the story starts with chronology and explores epiphanies and events giving way to thematic analysis and interpretation of common themes (Creswell, 2007). To reiterate, the design took place over time and was transcribed from the actual words through narrative dialogue from the survivor's life world.

It is important to realize that data from a phenomenological study of the lived experience description, whether oral or written, are never identical to the actual lived experience; they are transformations of the experiences (van Manen, 1990). Bracketing

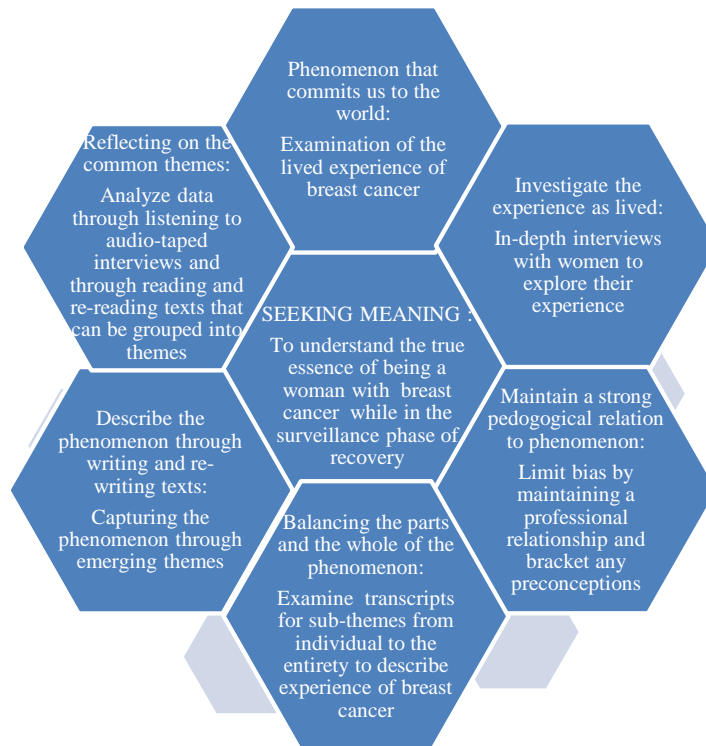


by use of deduction through a phenomenological approach is vital in overcoming the participant's subjective feelings, preferences, and expectations that would prevent coming to terms with an experience as it is lived through (van Manen, 1990). It was important to interpret each narrative as a brand new lived experience so that the participant's essence of the experience is heard and understood as it pertains to their life world.

Van Manen's (1990) methodical structure of six research activities provided a framework for interpretation by:

1. Turning to the phenomena which commits us to the world
2. Investigating experiences as we live it rather than as we conceptualize
3. Reflecting on the essential themes which characterize the phenomenon
4. Describing the phenomenon through the art of writing and re-writing
5. Maintaining a strong and oriented pedagogical relation to the phenomenon
6. Balancing the research and data within the context of parts and the whole.

Any lived experience description is an appropriate for uncovering thematic aspects of the phenomenon it describes. But it is true that some descriptions are richer than others. It confirms our experience that in our conversations or dialogues we tend to learn more about life from some people than from others. Nevertheless, when a person shares with us a certain experience then there will always be something there to gather (van Manen, 1990). The ongoing evaluation of the narrative is vital to continue to obtain thematic nuances for the final evaluation of the. The ongoing evaluation of the narrative was vital to continue to obtain thematic nuances for the final evaluation of the texts.



*Figure 2.* A dynamic interplay of the six research activities. Adapted by Amado (2014) from van Manen (1990).

Understanding the lived experience of breast cancer while in the surveillance phase of recovery can be seen by utilizing van Manen's (1990) six activities that give structure to a hermeneutic phenomenological type of inquiry. The above figure has the overlapping of the dynamic method to obtain a deeper meaning by examining the language in the narrative in which the story of the other is interpreted.

Through the hermeneutic phenomenological approach, understanding essences establishes a path to explaining the emerging themes in each story. This emergence gave the core meanings in the narratives of breast cancer patients and the impact they may have in understanding the lived experience of the phenomena of breast cancer during the surveillance and healing phase.

### **Research Rigor**

In evaluating trustworthiness of the findings, it was important to acknowledge what is presented linguistically of the other person's reality within a social construct (Bruner, 2004). Trustworthiness in qualitative research includes measures used to ensure the study is credible, dependable, confirmable, and transferable regarding rigor (Crotty, 1998). In qualitative research, the need for rigor and trustworthiness are important to enhance the research design being used (Creswell, 2007). According to Munhall (2007), trustworthiness consists of four criteria: credibility (truth value), dependability (consistency), confirmability (neutrality), and transferability (applicability).

### **Credibility**

Credibility is an important criterion for trustworthiness. It is a truth value placed on qualitative research of the actual study that replaces internal validity. It is an evaluation to make sure the findings are credible. This criteria is evidenced by prolonged

engagement, persistent observation, triangulation, peer review and debriefing, referential adequacy, and member checking (Munhall, 2007).

The use of intentional dialogue enhanced the description of the transcripts that the breast cancer survivors use. The emphasis on recurrent themes would warrant adequate time spent with the participants, which allows for the researcher to check perspectives and allows for the participants to assess for overall adequacy. Reflexivity, which is a dynamic process within and between participants and the data that informs decisions, actions and interpretations, is important in ongoing conversations while simultaneously living in the moment (Carel, 2012). By using this approach, it enabled the essence of the story and the interpretations of the breast cancer patient's experience to create meaning of the text without personal interpretations. By examining the themes, the voices of the participants transform the texts into possible future research with patients as a state of becoming and moving forward with a chronic disease.

### **Dependability**

Dependability assesses the process of data collection and analysis. In this study, dependability was obtained with accurate transcription by the researcher. By analyzing the actual themes found in each breast cancer survivor's language, there was a rich description of the texts. By ensuring accurate documentation of the narrative text including all field notes in the final report, the researcher described the sampling method, and the data collection method was described in detail so that other qualitative researchers can read them, evaluate the method, and deem the study useful and reliable.

**Confirmability**

Confirmability may be obtained through measuring how well the inquiry's findings are supported by the data (Munhall, 2007). The review of the data gathered within the context of themes supported confirmability. The findings and the synthesis of information enhanced trustworthiness. All data and themes were reviewed by the dissertation chair and committee. The data also were separated by emerging themes from each interview. Then, the themes were reviewed to see if there is repetition.

**Transferability**

Transferability is established when the findings from the study can be transferred to another similar context (Munhall, 2007). Prolonged engagement through use of thick description in a natural setting gave the researcher a detailed description of the context to allow transferability to be made by the reader for further inquiry (Creswell, 2007). The importance of the researcher to fully describe the detail of the phenomena and to see if it has relevance in a different setting was the responsibility of the researcher to make sure the findings from the study can be replicated.

**Chapter Summary**

This chapter discussed the methodology that was used for the study. It addressed the research design of a hermeneutic phenomenological inquiry to explore the lived experience of the meaning of breast cancer survivorship in the phase of surveillance. A description of data collection and analysis was reviewed, which also addressed reflexivity for the study and is important for analysis and trustworthiness.

This chapter reviewed the research rigor regarding trustworthiness. The importance of credibility is necessary in qualitative research and the need for accurate

interpretation of texts. The need for dependability by accurate accounts of themes and confirmability which allows for the synthesis of the above, and lastly transferability to make sure the study could have relevance in a completely different setting.

Based on the research proposal, the primary goal of this study was to set the stage for a rich hermeneutic phenomenological inquiry that explores the essence of the lived experience of women with breast cancer who are living in the surveillance phase of recovery and are facing long-term survivorship.

## **CHAPTER FOUR**

### **FINDINGS OF THE INQUIRY**

This chapter highlights the findings of the phenomenological inquiry of women living with breast cancer after initial treatment is completed as they continue under the watchful eye of the oncologist. The purpose of this study was to explore the lived experience of women with breast cancer while in a surveillance phase of the disease. This study allowed the participants to share their stories, thoughts, and feelings, depicting the essence of the phenomenon within the context of their personal journey with breast cancer. The life narratives of the women illuminated the meaning of their lived experiences as it pertained to living with a chronic, sometimes debilitating disease.

#### **Overview of the Process**

This chapter contains the findings of this hermeneutic phenomenological study in which the narratives of the 13 women participants were revealed through audiotaped dialogue. The close examination of the texts was an antecedent in seeking emerging themes to gain a deeper understanding of this phenomenon. By utilizing the dynamic interplay of the six research activities guided by van Manen (1990) the researcher was able to examine the data from in-depth interviews in order to understand and capture the true essence of the phenomenon through the emerging themes.

Fifteen participants responded to the flyers; however, only 13 participants met the inclusion criteria and were willing to engage in the face-to-face audio taped interview. The researcher contacted each participant by telephone to ensure they met inclusion criteria before confirming a time to meet. The recruitment process took a few weeks. Nine participants responded to the recruitment poster and four participants were recruited

via the snowball sampling method. Prior to the first interview, the researcher explained the research purpose, process, and expectations of the study. It was a slow and arduous process, but 13 women participated in the study. Informed consent was obtained for each participant at the time of the interview. Time was allotted at the beginning of the interview to complete the demographic survey and to clarify any participant questions. The participants were asked to select a pseudonym to keep their identity anonymous. The researcher collected data in face-to-face audiotaped interviews lasting approximately one hour.

The interview was akin to a conversation. In this type of interview information is shared in both directions with the format being relatively unstructured. The emphasis centers on the researcher listening to whatever the participant says as opposed to controlling or coercing the direction of the conversation (Carel, 2012). Gadamer (1976) has described this part of a hermeneutic phenomenological study as having the dialogic structure of question-answering that keeps the personal relation of the conversation intact. The researcher sequestered herself in a quiet home office while listening to the audiotapes before transcription began. After listening several times to the taped narratives, the researcher transcribed each narrative into text.

In order to suspend any assumptions and allow for bracketing, the researcher found it important to use field notes along with journaling to set aside any pre-assumptions. The time for reflection allowed the researcher to let the lived experience of the participant's story to come alive and to make sense to the researcher on a deeper level. Moore (1992) speaks of the modern epidemic of the loss of reflection on life experiences in order to have harmony in all matters: "A common symptom of the modern



life is that there is no time for reflection or thought, or letting impressions of the day sink in. Living with intention and living artfully, therefore, might require something as simple as pausing] (Moore, p. 160, 1992).”

According to van Manen’s (1990) approach of hermeneutical phenomenological writing the significance of anecdotal narrative in research and writing is to compel, to lead us to reflect, to involve us personally, to be transformed by another’s story, and to measure one’s interpretive sense and what it teaches. The journal also included observations of the participant’s body language, facial expressions, emotions, and other nuances that appeared throughout the interview. Journaling right after each session created an aesthetic expression that allowed the researcher to garner a more profound appreciation and understanding of the experiences shared and evoked a deeper understanding and meaning to the true essence of the phenomenon being studied. The use of writing distances one from the lived experience but also allows one to discover the existential structures of the experience being studied. Writing creates a distance between us and the world whereby the subjective of the everyday experiences become the object of reflective awareness (van Manen, 1990). This action was an important part of this phenomenological study in maintaining a pedagogical relation to the phenomenon, which diminishes any assumptions and limits the researcher’s bias.

Saturation occurred after approximately nine interviews, but the researcher continued data collection for verification and confirmation with another four participants. A total of 15 participants responded to the flyers; however, only 13 were interviewed due to inclusion and exclusion criteria. Journaling and immersion into the narratives allowed for a deeper understanding of what the women were experiencing as they lived with

cancer. The transcription of the audiotapes into text allowed the researcher to gain a better understanding of the participant's experience of the phenomenon. The researcher then went back after writing the verbal transcript, which was stored in a secured computer document, and listened again to the audiotaped conversations for any words, phrases, or nuances that may have been missed. The researcher then proceeded to examine the texts for repeated words and phrases from each of the participant's stories to ascertain patterns in vocabulary. This detailed review of the spoken and written words of each participant required the researcher to employ hermeneutic techniques aimed at maintaining the integrity of the original text. Following hermeneutic practices laid out by van Manen's (1990) six methodical activities, the researcher discovered common elements in the narratives, combining analytical reading with systematic grouping of repeated thematic phrases and words. Van Manen (1990) suggests three approaches to the analysis of data to isolate themes: (a) the holistic approach, in which we attend to the text as a whole; (b) the selective or highlighting approach, in which the researcher reads a text several times to determine what statement(s) or phrase(s) appear to be essential to the description of the phenomenon or experience being described; and (c) the detailed or line-by-line approach, in which the researcher looks at individual sentences and identifies what the sentence reveals about the phenomenon or experience being described. This study utilized (b) selective highlighting and (c) examination of the sentences in the text to uncover themes.

The researcher highlighted common words and phrases that appeared in the text that would help with clustering themes. The researcher then clarified themes in the margin of the text in order to see similarities in the narratives. After highlighting the

themes within the text, the researcher developed a list of words and phrases that appeared to best describe the categories that were extracted from the narratives and placed them on colored cards. This method of color blocking ensured the narrative description of the participant was repetitive in nature and common to the others before developing a list of words that appeared to describe the individual experience specifically. These words and phrases were then color coded and placed on the tri-fold storyboard in accordance with repetitive words and phrases obtained from the text. The color-coding helped to clarify differences in noticing patterns in the themes. Yellow was used for the first emerging theme, blue for the second theme, and green for the third theme. The color blocking of words and phrases created clearer categories that helped to extract commonalities in the narratives and place them accordingly under the appropriate theme.

After many days of reviewing the words and rearranging and deleting unrelated phrases, the major and supporting themes started to emerge. To verify the redundancy and repetitiveness of the themes, the researcher listened to the audiotapes again and reread the text for confirmation for a final time to ensure proper thematic analysis. The process of identifying themes utilizing van Manen's (1990) hermeneutic phenomenological approach was as follows.

The researcher obtained textual descriptions of the participant's story in their own words about the experience of the phenomenon. The dynamic process of the unfolding of van Manen's (1990) methodical structure of hermeneutic phenomenology helped guide this study and as defined below:

1. Examining the phenomenon and interpretation of the transcribed texts was essential in gathering the experiential narrative about the lived experience

being studied. The experience is captured in the language of the other.

Through listening and transcribing all the dialogue allowed the researcher to create a pedagogic reflective state for interpretation of the stories in order to develop a deeper understanding of the other's lived experience.

2. The researcher, through examination of texts derived essences through identifying themes or meaning from the participant's use of language. Writing of the narratives and reflecting on common words allowed for initial grouping into emerging themes.
3. The researcher proceeded to make sense of the writings, attempting to understand each participant's experience of the illness by reading and re-reading texts and examining words of each story shared. Investigating the experience as it was lived. Review of the spoken dialogue and constant examination of the narrative text helped clarify themes. Categorizing themes on paper helped make distinctions between the themes.
  - a. The researcher then had to find a way to be objective in the descriptive and interpretive of the subjective texts studied by finding common phrases after close evaluation of all the narratives.
4. The words and phrases interpreted were then categorized on repetitiveness in the narratives. This categorizing allowed the researcher to maintain a pedagogical relation to phenomenon.
5. The researcher after listening to the audiotaped interviews and close examination of the texts one last time began to make interpretive sense of the stories of the participants.

Hermeneutic phenomenology according to van Manen (1990) is premised upon that lived experiences are always meaningful and need to be captured in language itself and are constant interpretive and transitive experiences that capture human reality in a poetic, creative, and insightful way, rather than a procedural and rational method (van Manen, 2014).

Making sense out of being healthy and then suddenly being sick was apparent in the dialogues and was a constant undertone from the narrative data from this study. The notion of sudden change and disruption of one's timeline as in lived time and lived body seemed to propel them into a transitional stage while assimilating into their new reality. The participants while looking back in time and reviewing the memory of the illness were able to move forward and face uncertainty while maintaining and managing the disease process. A theoretical process of making meaning in the surveillance phase of healing occurred in response to a basic psychological problem of a threatened sense of wholeness and the fear of breast cancer's recurrence as well as the constant reminder of the illness while in this phase of recovery. This state is a place of limbo and a realm of constant observation. The emerging themes became evident after reading and re-reading the texts describing the lived experience of living with breast cancer. By connecting van Manen's (1990) six activities with examination of the nature of the lived experience, it became evident how each theme compliments and reflects a dynamic process. By utilizing a reflexive process in listening to their lived experience from the conversations, it was here the collaborative quality of conversation lends itself to the task of reflecting on themes of the phenomenon being studied (van Manen, 1990). Interpretation of the spoken dialogue became the material for phenomenological writing of their narratives and gradually

themes began to emerge. The emerging themes could be viewed in relation to lived time and lived body. All participants' exuded attributes that enabled adaptation to their life crises, which created a path to transition while in a state of limbo.

van Manen's (1990) approach to hermeneutic phenomenology was the guiding framework for this study. Data collection and analysis of this study was guided by van Manen's six activities mentioned above and the four existentials: temporality, spatiality, relationality, and corporeality as a framework to interpret the reflections in the texts.

The existentials are present in the narratives of the participants because they are a part of our daily lives, a part of our being in the world (van Manen, 1990). Phenomenological research allows the voices of the participants to reveal the essence that is brought out in their language of their lived experience. People shape their daily lives by stories of who they are and others are as they experience life. The participant's world is interpreted and made personally meaningful (Connelly & Clandinin, 2006). The main premise of a hermeneutical approach allows the words of the text to illuminate the phenomena being studied. People tend to create stories of whom and what they are. Therefore, semi-structured, in-depth interviews were utilized because they supported the study and the phenomenological approach. The purpose of the semi-structured interview is to gather narrative text that can deepen understanding of a phenomenon, while allowing the participants to tell their stories in their own words, thus promoting an understanding the phenomenon at a deeper level.

### **Sample Description/Demographic Representation**

Participants completed the comprehensive demographic survey to allow the researcher to gain a contextual group picture of the participants and a deeper knowledge

of the phenomenon being studied. Demographics may be helpful in future research endeavors that may come from this study. Participants were selected from a convenience sample of women finished with initial cancer treatment and receiving follow-up care. Fifteen women volunteered from the community, but only 13 met the inclusion criteria. All participants finished an initial treatment of surgery, chemotherapy and/or radiation and were under an oncologist care to present day. Obtaining demographics improves knowledge of this specific population and may reduce homogeneity in treating this population and eliminate any misconceptions about their physical, emotional, and spiritual needs while living in the surveillance phase of recovery.

The demographic revealed the following: The female participants' ages varied from 31 to 72, with a mean age of 54 years of age at the time of diagnosis. Their ages at time of diagnosis spanned from 29 to 71. The participants reported living with this disease from six months to seven years. The self-defined religious background of the participants included five Jewish, one Lutheran, three Catholic, and four Christian women. The participants also had diverse educational backgrounds, ranging from doctorate degrees, master's degrees, and undergraduate degrees. One participant was unemployed, two were newly retired, two worked part time, and eight of the women worked full time outside of the home. All of the participants had insurance at the time of their disease.

Four of the participants were married, four were single, two widowed, and three divorced or separated. More than half of the participants were diagnosed with breast cancer in their 40s or 50s, with the exception of one who was diagnosed at 29 years of age. One of the participants had breast cancer twice: initially at 42 years old and then

again at 49 years old. The oldest participant was diagnosed at age 71. Only four of the participants had a family history of breast cancer.

Although the stages for some of the women were more advanced than others at the time of diagnosis, all are actively in the surveillance phase and under the watchful eye of an oncologist. This specific time frame is a time of disease management that ensures the best quality of life for the participant while still living with follow-up appointments and medical management for as long as the oncologists deems necessary. As a result of each woman's diagnosis and specific cancer care regime the interventions vary. While all of the women who participated in this study were still in the surveillance phase of their journey, their stories differed in the pathways of liminality (transition) and returning to a place of acceptance in regard to living with the disease. The narratives revealed dealing with sudden change in their life timeline, transitioning in facing uncertainty, and lastly, acceptance and taking back control and moving forward.

### **Characteristics of the Participants**

Although the participants could choose a pseudonym only three chose to use one. The purpose of the pseudonym was to maintain the confidentiality of the true identity of the participants given the sensitive and emotive nature of the phenomenon. The interviews were sometimes very emotional for both the participant and the researcher. It was imperative to keep a distance in order for the researcher to bracket while also being immersed in the narratives. Even though at times it was hard to separate a therapeutic relationship from a research relationship, a comfortable, casual open dialogue became evident as the narratives progressed. With the use of a semi-structured dialogue and being present with each other, a sense of trust appeared in creating ease between the



researcher and participants. The description of the participants was extracted from the audiotaped conversations and transcribed immediately after the interview by the researcher. The researcher started the interview with casual conversation to make the participants feel comfortable before starting with the research questions. After a few minutes the researcher explained to the participant that the audiotape would begin and proceeded with the initial guiding question: what is the lived experience while in the surveillance phase of recovery? All the participants understood the term surveillance before the first question was posed and the recording started. This understanding was reviewed in the initial telephone interview to ensure the women understood what time frame surveillance referred to in this study. Each woman started their story at the beginning of their journey, their memory of the diagnosis, the past, the treatment phase, and subsequently the present phase of surveillance. The stories encompassed the initial diagnosis and the transitioning through treatment, surgeries, and the experience of living with cancer. All of the women fit the inclusion criteria, are post-acute treatment, and are attending regularly scheduled oncologist's appointment regardless of their stage of the disease to this day.

### **Donna**

Donna is in her late 50s and is a successful health care professional. She has earned a Master's degree in nursing along with her doctorate degree in nursing. She was diagnosed in her early 50s with stage III breast cancer and has continued to be under the watchful eye of the oncologist. She is married with two grown children and works full time as a health care professional. Donna initially had a lumpectomy with radiation and

chemotherapy and went right back to work immediately after treatment ended. Donna considers herself a very healthy person and work was a very good outlet for her: "I think I am strong and healthy and quite frankly when I went through chemo and radiation it was tough, I had my strength but looking back I sailed through it." Donna had a very good support system in her coworkers as well as her family. Donna has remained cancer free for the past seven years. She enjoys relaxing in her serene backyard. She stays active at her institution and exudes positivity and courage. She continues to see the oncologist and plastic surgeon for follow-up care.

#### **NeeNee**

NeeNee is a 43 year-old young preschool teacher. NeeNee is Catholic and is single with no children. She was diagnosed with stage one breast cancer at the age of 42. She initially had a lumpectomy with chemotherapy and radiation. She had been vigilant about starting mammograms early because her mom had died been diagnosed 16 years ago: "I was really good about everything so I didn't think I could ever get it." NeeNee works full time as a teacher. She feels that cancer has changed her as a person: "I am a different person because of it; a better person in a lot of ways." She continues to stay positive and has confidence while in the surveillance phase of her recovery. "Even though I have never really use that word (surveillance), it is where I am now, I still know that I'm being followed it is still there." She has a good support system with her friends and her family, and she also found a lot of comfort in her support group that she attends monthly. At times it was difficult for her to express herself, and the interview was punctuated by moments of silence.

**Susan**

Susan is a 54-year-old single woman. Susan was diagnosed at the age of 49 with stage II breast cancer. She had opted for a mastectomy and chemotherapy. Susan is Jewish and is active in her faith. She is currently divorced and has one grown son. At the time of diagnosis, Susan was working full-time in a very busy company. Presently, she is working part-time and continues to see her oncologist and family practitioner on a regular basis. Susan was active and took care of her body prior to her diagnosis. She went for mammogram and the diagnosis was not expected: "I was actually working and my son was 13 ½ years old and it just came out of the blue." She continued to work and be positive in the middle of all the changes. In the middle of treatment Susan decided to get a divorce. "I walked out and I said I'm done. I'm done. And that's been my change." Susan continues to be active with work and exercise and considers herself to be a spiritual person by staying active in her synagogue.

**Laura 63**

Laura 63 is a 48-year-old Christian woman who was diagnosed at the age of 46 with stage II breast cancer. Laura is married with no children. She works full-time as a registered nurse and is active in many nursing organizations. Initially, Laura 63 had a segmental mastectomy with chemo and radiation, and she continues to be on Aromasin, which is a long-term medication. She is actively under surveillance by the oncologist and plastic surgeon. Laura 63 is active in her church as well in professional organizations, which keep her busy. Laura 63 took approximately eight months off of work after treatment because of the fatigue: "I suffered from extreme exhaustion and fatigue and I probably went back to work too soon." Laura returned to work after an eight month

sabbatical and changed her work environment. Even though she says she still suffers from chronic fatigue and chemo brain, she is adjusting. Laura professes to stay healthy by exercising and juicing as many times a week as she can. She does her best to stay positive and does not always focus on the chance of recurrence: “I always know there’s a chance of recurrence but I don’t dwell on it because constantly thinking about it will not change it. I do the best I can to be positive.” Laura 63 has a good support network and is a strong believer in an Eastern-Western approach of medicine and healing. She believes in prayer and meditation, reflexology, acupuncture, and yoga. Laura 63 also is an adamant proponent of medical marijuana: “It was recommended to me by a doctor. I used marijuana to help me with my bone pain. It helps with my neuropathy; I could not sleep after all the steroids, my whole body hurt. I have to say those things helped me.” Laura 63 continues to mentor several women through breast cancer by volunteering with a local breast cancer foundation.

### **Esther**

Esther is a 63-year-old Jewish woman. She was diagnosed with stage II cancer at the age of 62. She had opted for a bilateral mastectomy followed by chemotherapy and radiation. Her treatment lasted approximately 12 months. She is currently retired and has two grown children. She is widowed but has a partner which she enjoys spending time with. She also enjoys being with her grandchildren and traveling. Esther has the spirit of a fighter. She was widowed in her 40s and had raised her children on her own. She dealt with adversity at that point after losing her husband and having two children to raise. At the time of her diagnosis she was working full-time and had lost her home, and eventually she lost her job and her health: “I don’t have the energy like I used to have. I

tire a lot easier.” Esther had a very complicated time with her chemotherapy and had some complications with her surgical site. She continued to stay positive and has a good support system with her two grown children and the support group at the hospital. Esther said that cancer actually made her family come together as a unit: “They came together as a cohesive unit for the first time in their lives.” Esther remains very active in her synagogue and in the community. She finds comfort in going to temple and helping others.

### **Nicole**

Nicole is a 31-year-old single mom of two young children. She works full-time and has an undergraduate degree. She was diagnosed at the age of 29 with stage II breast cancer. Upon diagnosis, it was thought that she had stage I, but with further testing it was diagnosed as stage II cancer. At the time of diagnosis it was deemed to be an aggressive type of breast cancer. Nicole was working full-time outside of the home and continues to work full-time and be a full-time parent. At the time of diagnosis she decided upon a bilateral mastectomy, which was later followed with chemotherapy and radiation. She continues under the watchful eye of her oncologist and her primary care physician.

Nicole is a positive person. At the young age of 29 she was diagnosed with breast cancer and it was a shock: “You know when I first found out I was diagnosed with breast cancer it was so random, I was there actually for something completely different.” She had no family history of the disease but remained positive throughout the whole journey. She has a very strong social network and a good support system with work and family. She considers herself to be spiritual. Even though the journey has not been easy she values life much more: “You appreciate life. You know I felt like in my life cancer festered

because I was at a very unhappy place and I was always trying to make everybody else happy. I was turning into an unhappy soul. And that's where I feel that's where the cancer attacked." After her surgery and treatment Nicole divorced her husband. She had decided that there was no time to waste being unhappy: "I choose something that I want to do yeah, so time is definitely a huge variable in this, hundred percent. I feel that my kids keep me going." Nicole is presently under active surveillance every four weeks due to fluctuation in her cancer markers. She sees her oncologist every six months and every three months she goes to her gynecologist. She continues to eat well and exercise. She continues to stay positive and face the adversity with great strength and courage. Her brevity was contagious.

### **Jackie**

Jackie is a 60-year-old woman of Jewish faith. She was diagnosed at the age of 57 with stage II triple negative breast cancer. Jackie opted for a mastectomy with chemotherapy and continues to be under vigilant care by the oncologist. Jackie works part time outside of the home and is single. She has two grown children. At the time of her diagnosis Jackie was working full-time at a non-for profit autistic foundation. Autism is very important cause to Jackie's due to the fact that her grown son struggles with the condition. Jackie remains dedicated to helping others who struggle with autism. Presently Jackie works part-time and is adjusting to her new reality: "It's interesting because you go through stages; it's taken me three years to finally feel comfortable in my own body. So definitely it is a journey on so many levels." She refers to the memory of breast cancer as a constant presence: "So there's never a day that goes by and I don't think about it, I was having trouble with my finger and I said oh my God is the cancer

back? I'm more vigilant about getting things out, I want to be monitored." Jackie is a proponent of aesthetics as a holistic way of healing: "I went to healing touch twice a month for a year and I did take advantage of that. To me it is those deep relaxation techniques that [are] very necessary; it keeps me calm just like at the Morakami and that came at a time in my life when it was really bad." Jackie has said breast cancer has changed her in a positive way: "Well I've always been a positive person by nature but I think even now I'm more positive. I know that stress is unhealthy and I do believe stress played a big part. But I really try to look at the positive." Jackie finds adjusting to the illness and helping others allows her to cope better in the everyday happenings of life. She exuded quiet confidence and courage about facing her journey and transitioning by serving others, which she shared in the following:

Helping other people through it I think that was also a huge thing in my healing, to me it was all about paying it forward. That made a huge difference for me, huge difference. If I could help one other person get through this and use this even if it was telling them about rinsing their mouth after chemo. When you see the fear in someone else and you know that you were in that position one time it's a good thing to be able to show someone that are strong now still and can get back to that place, your comfort zone, it is kind of part of the healing process.

### **CDiddi**

CDiddi was diagnosed at the age of 47 with stage I triple negative breast cancer. CDiddi works full-time in pharmaceutical sales and is slowly adjusting to her new normal. She is a Christian and a single active woman with no children. Her knowledge

of the disease was greater than normal due to her educational background. She had an extensive background in oncological pharmaceuticals: “I had some experience and knowledge of this and it was in oncology and I was in pharmaceutical sales I was very close and this was near and dear and much unexpected. I got everything done pretty fast. I just wanted to be super aggressive.” She opted for a bilateral mastectomy followed with chemotherapy. Triple negative cancer has a different regime than other cancers, but she was very aware and educated about her disease. Unfortunately, when she was diagnosed her mother was dying of cancer as well. She was taking care of her mother and also going through her treatment. However, she had a good support system in her coworkers and friends. She considers her surveillance phase as being constantly watched: “I think it means watching, making sure you just consistently watching and looking for signs, you have to be aware of things. You have to know your body.” Cdididi exercises and walks and eats well. She continues to stay positive and move forward. She lives with awareness everyday: “I don’t think you experience the highest highs unless you experience the lowest lows. I look at life’s hills and valleys and that’s the way to be you got a rock through them.” She finds comfort in sharing her story: “You need to get it out.” CDiddi continues to journal and work, and she enjoys traveling now more than ever.

### **Ronnie**

Ronnie is a 56-year-old Christian woman who was diagnosed at the age of 55 with stage I breast cancer. She is presently single and has two grown children. She opted for a lumpectomy, chemotherapy, and radiation. She continues with oral anticancer medications and see her oncologist on a regular basis. At first, Ronnie was guarded with



sharing her story. She had expressed that it was a very traumatic experience: "I was very shocked when I was diagnosed. I thought that it was in the best health I've been in, in a very long time." Ronnie works at a very busy practice helping women and children in need. She does community crisis intervention and is very dedicated to her job. She continued working throughout chemotherapy and radiation. Along with battling cancer, she also cares for her elderly mother who is battling Alzheimer's disease: "It is very draining to and I'm still doing it and I'm the only one doing it. When I was diagnosed with cancer I had to put her in an assisted living facility." She went to the support groups initially, but found most of her support group through her church friends and family. She is very active in her church and her prayer group. She believes that trying to help others initially has made her grow: "I think I have grown more as a Christian - maybe that's the purpose, to become more honorable and godlike and strengthen me." Ronnie seemed to have a hard time dealing with the changed body image in regards to finding someone to share her life with: "I don't want to be alone the rest of my life. I am afraid to tell somebody if I start dating because they might say she's sickly. They might not want to date me." Ronnie continues sharing her story about breast cancer to other women and encourages early detection. She continues to be active in the crisis outreach program and is very dedicated in helping other women move forward in their lives.

### **Mary**

Mary is a 73-year-old woman of the Catholic faith. She was diagnosed at the age of 72 with stage II breast cancer. Mary initially had a lumpectomy, followed with a mastectomy. Mary is widowed but presently has a partner and has two grown children. She is a retired registered nurse and stays active in the community. She loves to play

tennis and travel. Mary was diagnosed late in life but seems to have a matter of fact acceptance of the disease: “It’s really been easy for me to have breast cancer because of all the other issues with my son and daughter, the breast cancer I can fly right through it. It’s not a hard thing.” Mary has been the primary caretaker of her daughter and son who have struggled themselves with addiction and chronic illnesses. She had claimed that breast cancer was a good thing: “Yes that’s why I said breast cancer was a little bit of a relief to me. I have been dealing with their things for many years.” Mary continues to go every three months to see the surgeon and every three months to see the oncologist. She volunteers at a children’s shelter and continues to stay active. She considers herself to be a spiritual person: “I’m Catholic but I don’t go to church every Sunday.” Mary enjoys relaxing and botanical gardening. She enjoys traveling with her partner. Mary shared that being under surveillance makes her feel safe: “It means being watchful: my oncologist is going to watch me for the next five years and then forever after that. Yes, it makes me feel safe, checking my blood, it makes me feel that if this should recur will get it early and will take care of it.” Her mantra is to stay busy and active every day: “I have thought about it and I wouldn’t change anything, time is always been important to me. I know we are not here infinitely.”

### **Lisette**

Lisette is a 49-year-old married mother of two teenage sons. She was diagnosed at 48 years old with stage I breast cancer. She opted for a lumpectomy with radiation. During her treatment she also underwent a hysterectomy for fibroid tumors. She had been on tamoxifen treatment but had side effects and claimed her quality-of-life was diminished: “I was that 2% that had a bad reaction to tamoxifen so I had to go off of the

tamoxifen.” At the time of diagnosis she was working full-time outside of the home. Presently she is working full-time from the home. Lizette is an accomplished artist, and her painting gives her much joy. Her dream would be to help other women express themselves through the arts: “I would love to start up a program like that seriously, like painting tile, or something, or making a bracelet, it doesn’t have to be anything crazy specially while you’re sitting there and putting chemicals in your body it seems like your body takes it much better.” She has a good support system of friends, family, and the support group. She continues trying to cope, but says she has difficulty in transitioning to a new normal: “I didn’t think almost after 18 months I would be grappling with all the stuff that comes afterwards.” Lizette continues to exercise and eat healthy. Even though sometimes the ambiguity of the disease gets to her she keeps moving forward: “You don’t know who to call for anything.” She continues to take an antidepressant for mild depression but is weaning herself off of it. Lizette enjoys meditation, garden walks, journaling, and painting. She felt solace and comfort in painting through her illness: “I have a painting in the other room of my illness and I did it when I was going through treatment and went through a lot of interesting steps so most of my paintings are abstract and not representational of anything but were really fascinating to do.” Lizette conferred that stress possibly had something to do with the onset of her diagnosis of breast cancer. As she shared her story she had also shared that she had felt stress and a loss of control in the past prior to being diagnosed. She had shared that stress was a major factor in her illness: “I do think stress played a part in it. As I said before we were in New York on 9/11, my husband lost his business, I lost my job, we just finished renovating a house and we had a 4 and 5-year-old. So we had a lot of stressful things for very long time. A high

concentration. It was just one thing after another. Boom, boom, boom.” She stays busy with work, raising her children, and her art. She believes breast cancer was a catalyst for change: “Like it was just brewing before-hand, so breast cancer was a catalyst, a catalyst for change. Yeah it was brewing. All of the sudden you say oh this makes it so clear to me.”

### **Sherry**

Sherry was diagnosed at 53 years old with stage II breast cancer. She had a lumpectomy followed by chemotherapy and radiation. Sherry is of the Jewish faith and is very active in her synagogue and in her faith. Sherry lives with her mother and is single and works full-time outside of the home at a senior citizen community. Sherry still is under the watchful eye of her oncologist. Sherry had shared that it was initially a shock because she had taken care of herself. She had exercised and ate healthy, did not do any drugs, and only drank socially: “So my initial diagnosis my initial feeling was shock and all I can say is God I’m going to die. That’s all I could think of because I was scared.” She had shared that everything went very fast. Everything was at an accelerated pace, and she felt that she had no time to think. Sherry lives at home with her 79-year-old mother who is also a breast cancer survivor. She is very connected to her breast cancer support group. She feels that by helping others through this makes it easier on accepting her diagnosis: “Sometimes I can help with the question I can participate in that, so I feel that if I can help a person get through this then I did something good.” Sherry tries to enjoy life more these days. She said she had a bucket list and one of her check offs on her bucket list was to buy convertible: “I swore when I got through this I would buy myself a convertible and I did, I try to enjoy life.” Sherry remains active in her

support group in her community. She continues to work full-time and stay active in her synagogue.

### **Hinda**

Hinda was diagnosed at 42 years old and then again at 49 years old. She was diagnosed with stage I breast cancer, for which she had surgery followed with radiation. She had a complicated reconstruction surgery and continues to be under surveillance with the oncologist. She is married, has two grown children, and has recently retired. She views her breast cancer as never ending: “I know it’s never ending.” She shared that after breast cancer there were other things that began to affect her health. She shared her became depressed on the tamoxifen: “I was devastated. Probably knowing that I was on a cancer drug made me even more depressed.” Hinda had a hard time recuperating from the surgery. She was active prior to her cancer diagnosis and exercised and biked on a regular basis. She was an avid swimmer and after her surgery she was unable to do so: “I think I have my emotional strength back but it took me five years, it was hard to get my mind wrapped around the fact that I’m a different person. I just can’t do the things I used to do.” Hinda is very active in her community and her temple. She claims the synagogue gives her a sense of purpose: “I try to make meaning out of it, that’s the way the cards were dealt. It was God’s plan.” She also shared that by moving forward she had to surrender and accept help from others. Hinda stays active in her temple and in the community with helping others in need.

### Themes

Themes are the essence of an experience as viewed from the participants' perspective. It became apparent that all participants demonstrated a large degree of determination and resilience through close examination of the narratives. The themes highlight the lived experience of the women living with breast cancer. The life worlds that reflect van Manen's (1990) existentials are represented in space (spatiality), time (temporality), body (corporeality), and human relation (relationality), while living with the challenges of surviving cancer. According to Ugarrizza and DeSantis (2000), in phenomenology, words, phrases, and sentences abstracted from an interview are labeled variously as themes, forms, areas, and processes. The themes, forms, areas, and processes are then grouped into what are variously called theme clusters, themes, categories, and essences (Ugarrizza & De Santis, 2000).

Three major themes emerged from reading and re-reading the stories of the participants: (a) transilience, (b) transition, and finally (c) acceptance. These themes were not specific to a participant because all or some of the participants may share the overlapping of each theme. The constitutive pattern was transitioning from health to illness. Women experience a precipitous change in their lives after a diagnosis of breast cancer. How they mentally, physically, and emotionally approached diagnosis and treatment affected their lived experience and future outcomes while living with breast cancer.

The concept of liminality emerged as the essence of what surveillance means in the lived experience. In studying cancer survivorship in the phase of surveillance, liminality may facilitate our understanding of this phenomenon as women transition to

**Comment [JA1]:** I am not sure what you are trying to say here.

survival and create an improved quality of life. Liminality traverses the breast cancer continuum. It is a time between diagnosis, treatment, and the unknown future while living with cancer. The term liminality is attributed to anthropologist van Gennep, who used it to identify a quality of transition in rituals, “betwixt and between” a rite of passage (Turner, 1969). The pathways of liminality were threaded throughout stories of the participants. The overlapping themes of transilience, transition, and acceptance were essential characteristics of moving forward while facing constant uncertainty.

The first theme that emerged from the narratives was transilience; a sudden change is viewed as a disruption in one’s life. It is a time of facing the uncertainties of cancer and preserving our former self as one looks back at the past and begins to let go of the old self, emotional and physical. Looking back in time the memory of the illness was essential for the acceptance of facing choices and decisions of living with cancer presently. A conscious awareness of time was an undercurrent in mostly all the narratives. Time and memory are interwoven throughout this study as it relates to the liminal pathways of transilience, transition, and acceptance in order to assimilate into a new reality. Memory was viewed as a way the participant remembers or recollects the initial news of the diagnosis, the treatment, the journey, and fears of ongoing health challenges and the possibility of recurrence and facing death and dying. The second theme was that of transition. Liminal pathways of transition as the second theme were evident in the narratives. The transition is the time of being in limbo. Managing and adjusting to the illness is crucial at this point. It is where one is no longer the old healthy self but has not accepted the new self. And lastly, there is the theme of acceptance, which is a dynamic interplay of all the themes and essentially a returning to the old self

and a place where the participant begins to take control within the uncontrollable while living with breast cancer. This place is one of transition and immersion into the new self. Many of the participants exuded a resiliency to change more so than others. The letting go and managing the disease and sustaining in a world of uncertainty manifested differently in their coping with breast cancer. It is common among experts in social sciences to find certain components in resilient people. Ramirez (2007) suggests that resiliency can be seen in education pedagogies as well as the social sciences to explain how a person may or may not reintegrate an improved way of life after adversity.

Letting go, assessing, living with ambiguity, and integrating illness into one's life facilitated a return to a new normal for all the participants. Some of the participants more so than others learned how to integrate the challenges of chronic illness into their everyday lives better than others. The past, present, and future merge to create a conscious awareness of how they will spend today as well as the rest of their lives. Liminality emerged as the true essence of surveillance in this study as it relates to moving on in life and creating a new reality. For the purpose of this study, it is important to define liminality as it relates to the attributes of the themes of transience, transition, and acceptance. Liminality is a place that is not a place, and a time that is not a time. Liminality is cunicular, like being in a tunnel between the entrance and the exit (Turner, 1969). This concept will be discussed in detail in Chapter 5.

Through reflection on the lived experience from the time of her diagnosis to the end of acute treatment, each participant mentioned the similar attributes that embodied the lived experience of living with breast cancer. The surveillance phase of recovery is a time of "betwixt" and "between." It is a time that all the survivors have in common. For



the purpose of this study, there are many factors that relate to adapting to adversity; however, the emergence of transilience, transition, and acceptance were interconnected and evident throughout the narratives and overlapped at times throughout the participants' stories to create a rich, textual description of their lives as they experience living with breast cancer. The themes became major attributes of ways the women expressed a path to wholeness and made meaning of the disease.

#### **Transilience: Sudden Change in Life's Timeline**

The first emerging theme was transilience, a sudden change in one's life timeline. Transilience refers to the abrupt change in a person's life evidenced by a crisis, and is a time of letting go of the old healthy self and a reflective place of looking back in time from the moment of the diagnosis and the words of "you have cancer" to a new lived time and a path of choices. Time is sequential as it pertains to the participant's journey through the trajectory of care. Time was explored as the past event of obtaining a cancer diagnosis, receiving treatment and interventions, and finally a recovery phase where all acute treatment is finished. The timeline of each participant recalled the past, present, and future as life moves forward. Hammond (2013) postulates nature of time-consciousness is one of the central themes of phenomenology and one that all major phenomenologists have addressed at length (Hammond, 2013). The constant looking back at a lived experience and looking forward changes the perception of that experience as it capsulized in the recent past and projected future (Hammond, 2013). Memory can be seen in representations and manipulations of time within the context of the illness being experienced (Frankl, 2006).

Transilience is seen in the participants' stories as a disruption of temporality and corporeality - a sudden change in one's life. Transilience is the time of diagnosis and is the first step in the liminal pathway of healing. There are evident steps in transilience as it relates to living within the context of illness. Transilience is evidenced by the following experiences shared by the participants: (a) being healthy and then becoming sick; (b) letting go of the old self both emotionally and physically, a time of losing control; (c) looking back in time at the memory of the illness; and (d), becoming aware of facing choices and decisions in order to transition through the uncertainty. The transition from illness to an accepted state of wellness is a dynamic process. It is a journey of vacillating between the initial crisis of being told you have an incurable disease to navigating through treatments and doctors' appointments warranting challenging times. As Sherry stated:

So my initial diagnosis I was in initial shock, all I could say is God I'm going to die. That's all I could think of because I was so scared. I went to a bunch of doctors so I saw the radiologist, social worker, surgeon, and then we would go from there. So I saw those guys three days later and everything was going very, very fast.

The sudden change created a state of instability for many of the participants. The experience of a diagnosis of breast cancer disrupted their sense of continuity and at times created a weakened state of body, mind, and spirit. The routine of everyday life was no longer intact. By sharing in conversation the experiences of the past were explored and allowed the participants to probe new ways to cope while living with breast cancer.

Susan shared: "Yes, time is precious. I go back and think about having cancer a little bit

more, it makes me put things on my schedule a bit sooner.”

The importance of recalling the illness experiences in the present with short-term (or working) memory is vital to understanding the lived experience in the present tense. However, the way one stores past events and learned meanings in long-term (episodic or semantic) memory helps to prevent the memory of the illness becoming too malleable (Kandel, 2006). Along with sharing their stories from diagnosis to present day, there was a common tone of anticipation of what the future may hold. Again time was an invaluable tool that the participants’ spoke of in order to make sense of life at the present moment and in moving forward. The timeline encompasses a disruption of temporality and live time in regards to an unexpected diagnosis of cancer. Looking back in time many participants recall the illness as a disruption of their old self. As NeeNee shared: “Well, the diagnosis was just a shock. My mom had breast cancer like 16 years ago, but I’ve always been passionate about raising money and raising awareness, so I started mammograms early so I didn’t think I could get it.” It is a sudden change to a person who at one point in time is healthy and in an instant becomes ill. As Susan said, “All of the sudden something happens and women go for their mammograms and then something else happens in the next diagnosis was cancer.” Many of the women felt a loss of control. As Laura63 explained, “After I finished treatment and I had to be seen by a physician every week I freaked out. No one told me that was a normal phase and that I had to see a physician to evaluate me every week it was strange and unsettling. Suddenly I was out there.”

Living with illness evokes fears relating to loss of health and possible recurrence of cancer. Some participants responded differently to the diagnosis than others. The

youngest participant, Nicole, was diagnosed with breast cancer at the age of 29. Nicole shared:

You know when I first found out that I was diagnosed with breast cancer it was so random, I was there for something completely different and then he diagnosed me and it was cancer. I said okay what do we do next? It was spreading. I cried from the appointment to work in my car.

Nicole was raising two small children as a single parent and the diagnosis came out of nowhere. It was a time of facing choices and decisions like many of the other participants. The trauma of the diagnosis was abrupt and sudden and at that very moment became a gateway into an emotional journey. As de Beauvoir (1965) expressed, "Cancer, thrombosis, pneumonia: it is as violent and unforeseen as an engine stopping in the middle of the sky." All the participants had to maintain life while struggling with the diagnosis of cancer and learning how to transition with all the uncertainties and the disruption in their self-identity.

#### **Transition: The In Between Time: Limbo**

Transition was evidenced in many of the narratives as the in-between time of waiting, and being in limbo as it pertains to facing the uncertainties of breast cancer. All of the participants, while struggling with the active disease of breast cancer, tried to maintain and adjust by staying positive, working, and creating a social support network in order to cope with cancer. Transition is a time of adjusting. It is the time of vacillating between wellness and illness and integrating the disease into the new way of being. It is a place where the participant's life as a normal healthy woman has come to when an end and has been punctuated by illness. This point of surveillance, the living in limbo

between the appointments, the ambiguity of the disease itself, and fearing recurrence, is a crucial point in the healing process. The participants live time, lived body, live space, and lived human relations are all redefined. By fostering transilience and modes of transitioning there is a sense of acceptance and the ability to move forward in life. The spoken words of many of the women were muffled at times with tears and the sense of going back in time was both scary and illuminating. As Jackie shared:

Well it's interesting because you go through stages; it's taken me three years to finally feel comfortable in my own body. In the beginning you're so actively fighting because of the problem, the cancer, so definitely it is a journey on so many levels. I continue to be hyper vigilant, but I don't dwell on it I have to stay in the present. I can look back over my journey and embrace it. It could've been a whole lot worse.

Transitioning time in this study can be viewed as a construct pertaining to time in the present state of being well or ill and time waiting for future possibilities of progression or recurrence of the disease, time spent suffering, and time left as it relates to facing one's mortality. The health and illness transition manifested differently in some of the participants. In adjusting to a new reality the participants assumed responsibility for their health and tried to regain the best health possible by creating new habits of a healthy diet, exercise, and maintaining a positive attitude as it relates to this time of being in between wellness and illness, which is the time of surveillance and the time of uncertainty and living in limbo while being treated and adjusting to a chronic illness. The time in the liminal pathway is the time where the person manages the disease as best as possible. Transitioning time is the time of living with the ambiguity of the disease itself.

This time in the liminal pathway is a major adjustment time. In this in-between time many participants underwent transition by initially (a) facing uncertainty, (b) maintaining while struggling with the disease and of the fear of possible recurrence, (c) adjusting, staying positive, utilizing social support networks, and also alternative creating modes of healing, and finally, (d) deciding on the type of treatment and managing the disease process as it related to their particular situation. As Lisette says:

You caught me at an interesting time because two weeks ago I stopped taking the tamoxifen. I had a come to Jesus moment. I was just like I have to go off of everything. Never in a million years did I think that 18 months after being diagnosed I would still be grappling with all the stuff that comes after words. Like I was thinking you survived the treatment, you're done, I could move on mentally; I am so not there. I'm not there at all. You know once radiation is over and treatment is over the connection to the drop doctor drops way off. You don't know who to call for anything.

It appeared evident that space, spatiality, and time, in reference to van Manen's (1990) four existentials of phenomenology, were threaded throughout the narratives. They became a liminal place where recovery began. In that moment in time when the participants recalled the memory of the beginning of their journey where time, temporality, and space merged to create an existential understanding of their illness at that moment. Although the experience of illness can be different for each person there are identified commonalities in the narratives of the survivors. Breast cancer disrupts the relationship between one's body and the environment. Illness modifies time after diagnosis, especially if the prognosis is uncertain. Both give an amplified sense of

mortality, and a sick person may revise what one thinks of as optimal use of time (Carel, 2010). The melding of memory and time molds the elastic properties of time whether it is a good memory or a bad memory (Hammond, 2013). As Jackie said:

There are so many experiences around being diagnosed and everything happening and I think women often defined ourselves in many ways: my hair was lovely and I was a large breasted woman. I lost my hair and then I lost my boobs needless to say it was traumatic. I never wanted to go through this again. There's not a day that goes by that I don't think about it I do think about it at times like if I have a pain in my neck or if I have a pain in my leg. I am more vigilant about those things and I want to be monitored more closely. You are so busy fighting for your life you are doing all the things you have to do and then all of a sudden it's over. And then everyone around you says oh it's over you're done. Life is supposed to be back to normal. Which you know isn't the case at all and all of the sudden one day you wake up and say holy moly I had cancer, I had cancer. And it was real. Everyone expects you to be normal again, whatever normal is. Whatever normal was. Now it's the new normal.

The transition from illness to an accepted state of wellness is a dynamic process. It is a journey of vacillating between the initial crisis of being told you have an incurable disease to navigating through treatments and doctors' appointments. The recovery process for survivors of a critical illness is an important but under-researched area, particularly from a qualitative perspective. Exploration of the impact of the intensive care experience, including ongoing memories for the patient, is only now emerging in the literature (Papathanassoglou & Patiraki, 2003).

Again recollection of past memories of the entire sequence of the events of living through a diagnosis and treatment was an invaluable tool in which the participants spoke of in order to make sense of life at the present moment. CDiddi stated, "I am aware of how I spend my time. So I started going back to work part-time but there are moments when I think, can this come back? Everyone goes through that. Things I can't control I can't, you gotta let it go." The memory of the initial news of being diagnosed with cancer and then moving along the path of treatment to the time of the present moment was situated in their memory. In order to make sense of the present situation the participants had to recall the past in order to transition to the present and accept the future while living with cancer. As Susan said:

Everybody comes up with the idea that after you've had cancer you come up and smell the roses, the little things don't count, to me there's some truth in it but it doesn't change the way your life is because I really don't think you completely change yourself. You are who you are. Physically you are a lot different; your essence is your essence. The little things that bothered you before still going to bother you afterwards. If you didn't look at the glass half-full before you can't look at the glass half-full now. But there is something that did happen.

Explicit memory makes it possible to leap across space and time. Recalling a memory episodically, no matter what the memory is a creative process and allows for an individual to recollect an event elaborate and reconstruct, with subtractions, additions, and possibly distortions of the life altering event (Kandel, 2006). "I see life as too short. Too many people around me are coming down with illnesses and are just passing away. I worry about that," said Sherry. Transition is a liminal phase, and it is a dynamic process



found in this study in order to facilitate acceptance and moving forward. Facilitating transition has been identified as being a center concept for nursing (Meleis, 2010). The above mentioned steps of transilience and the steps in transitioning illicit a pattern for transformation and integrating breast cancer into their forever changed lives.

Transitioning creates a space of redirection and acceptance while living with cancer.

### **Acceptance: Moving Forward**

The third theme is acceptance and the ability to move forward in time with this disease. Acceptance in the narratives of the participants were reflected in the following: (a) positivity, (b) social and spiritual connectedness, (c) returning to the old self, back to the future while incorporating holistic ways of healing, and (d) making meaning out of their diagnosis by helping others. In the liminal pathway facing breast cancer and accepting the new self is where the participants returned back to the future to the old self while creating a new self in the realm of breast cancer. This stage is where the participants seemed to take an active role in healing and accepting cancer as part of their new normal and took responsibility for their health. As Donna shared:

While the radiation was a bit easier than chemo I went every day and I took care of myself and I paced myself and I knew that it had a cumulative fact, a fatigue factor but I would finish my chemo on Friday afternoon and had the weekend to recover but working helped me. I took two classes that semester. I knew if I had chemo on Fridays I knew that Tuesday was not going to be a good day, I mean I had the option or luxury of not taking care of patients. I could come to my office shut the door and you know some days on Tuesday I would just go to my doctor's

office to get a liter of fluid because I was feeling dehydrated. I had such great support even the president of my company said that I would always have a job and you have to do what you have to do.

It was important to all the participants to believe in someone or something to facilitate moving forward. Almost all of the participants exuded positivity and courage. Their connection to a strong social network and spiritual connectedness facilitated a transition while working toward acceptance. It became clear in the examination of the narratives and analyzing the texts that all participants demonstrated a considerable amount of faith, despite their diagnosis and possible mortality. While faith manifested itself in spiritual beliefs and/or practices it also manifested in closer social relationships. There was also an appreciation of the fact that they had support in a variety of ways, including family and friends. Some spoke of the importance of relationships. The participants seemed to find comfort and solace in sharing their story with others. “I try to see it is my goal to get through it and get to some kind of normal. As far as eating healthy and things like that you know. And spending time with family and friends as much as possible,” CDiddi shared. Many of the participants stayed positive by continuing to work full-time and staying connected to friends and their support groups. Many of the women began transitioning through exercise, better nutrition, and holistic ways of healing such as Reiki (healing touch), gardening, writing, and painting, creating a pathway to becoming stronger. Jackie said of holistic healing:

I went to healing touch twice a month for a year and I still go once a month. To me it was just one of those deep relaxation techniques and was very, very necessary. It helped calm me down. Being able to journal and sort of collect my

thoughts and figure out where my next move would be was huge and really helped me find myself. I think breast cancer for many people makes you realize how precious life really is. How tentative life is and how important it is to feed your soul in a way, in the middle of all the hustle and bustle of everyday life you tend to cite of that, here this is where I go [Referring to Morakami Gardens].

The passive transition to the point of acceptance manifested differently in each of the participants. Some made work a major part of transitioning because it created a sense of normalcy. As Donna shared:

I stay busy and I don't necessarily remember that I am a survivor. I will tell you the most days I don't remember that I had cancer which is very good for me. I think I'm strong and healthy and I worked went through chemo and radiation. I think I may be missed five days of work so I said I could move through this.

Similarly, NeeNee shared:

I was working through the whole thing full-time. I had switched jobs which I didn't think I could do. I didn't think I could work with autistic kids so I knew this new job going through the treatment, that I could do that if I did that then I can do anything. Not only did I beat breast cancer but I learned much during the year. I needed to be with my school family it really helped me and kept my spirits up and it kept me going.

Some of the other participants looked at life differently. Lisette shared, "I don't want to sit at work all day. I am a painter. I have a bunch of paintings in the other room; I would just love to paint all day. I want to do what I love." Many of the women

thought, through examination of their narratives, by acquiring this disease it seemed to prepare them to help others who were facing the uncertainties that accompany the diagnosis of breast cancer. The disease gave them a renewed sense of purpose to their life. As Sherry stated, in regards to reaching out and social connectedness:

I said let me go see what this is all about and I met a bunch of wonderful girls.

And I still go every second Wednesday. Sometimes I can help with the question a lot of the time and I can participate in that because if they ask about certain things about a chemo port or about the chemo then I can tell them what worked for me.

So if I feel that I can help a person get through this, then I did something good.

Making sense and giving meaning to the illness or to convince oneself that all things happen for a reason was in the forefront of each shared conversation. Making sense out of a traumatic event such as cancer led the women to be authentic in how they are living their lives in the everyday. Many tried to make sense of their physical and emotional suffering. Esther shared:

I get tired and I have headaches and pain and I go to the doctor all the time. Oh yeah I still do that. Because I guess I'm afraid. You look at life so differently, that chemo almost killed me. But I also don't want to go through it again.

The participants had a keener conscious awareness of time and how the use of time was so different now that they are living with a chronic illness. Many of the participants viewed life with breast cancer as a waiting game: the "betwixt and between" time. As Ronnie shared, "Unfortunately I'm wasting a lot of time. I just wish I would hurry up and get the strength and encouragement to be out there and enjoying life. I don't know what I'm waiting for."

van Manen's (1990) existentials of spatiality, corporeality, temporality, and relationality were recognized within each story and became a guide for reflection as a part of being in the world. Lived space (spatiality) is the actual environment or felt space, and it is an existential theme that refers to the world in which human beings move and find themselves at home (van Manen, 1990). The lived body (corporeality) that van Manen (1990) refers to a phenomenological fact that each human being is physically in the world through bodily presence. Another major premise to this study manifests in lived time or temporality. The notion of lived time is subjective and differs from person to person. Lived time becomes a temporal and cognizant way of being in the world. Lastly is relationality, which reflects the human relationships and the interpersonal space that is shared within a social construct. Each existential manifested in the fabric of the participants' stories during the interpretation of the texts. These four existentials of lived body, lived space, lived time, and lived relation to the other can be differentiated in a phenomenological study but not separated (van Manen, 1990).

Almost all of the women shared a sense of vulnerability with the prognosis and the uncertainty of their illness. It became evident that all of the women recollected the journey in sequential stages. All of the participants spoke of the past, present, and the future in relationship to lived experience of the surveillance part of the journey: the past, early recollection of diagnosis, the middle phase of navigating treatment, and lastly facing the present uncertainty of living with cancer and possible fear of recurrence. "I still believe somehow it's better to verbalize it. If you can find somebody that you can just talk to, tell your story. Just get it out," as CDiddi shared. Almost all of the participants were able to transition and let go of the stigma of cancer survivor identity in

order to move through the experience. NeeNee said, “I never thought I was going to die from this. You’re not fighting for your life; you’re fighting, fighting to get past this part of your life.” The liminal state is dynamic, fluid, and without clear direction but creates an opportunity for significant growth and personal development (Kelly, 2008).

### **Liminality: The Essence of Surveillance**

The strength and hope the participants gained through reflection attributed to making meaning out of the illness, which garnered an improved adaptation to their chronic illness. Liminality bridges the gap between each theme. A liminal threshold requires us to stand on an unfamiliar threshold, not knowing how to proceed. As we tremble before the wilderness of the unexpected we realize that our destination, a new plateau of safety and security, remains completely veiled. We lose aspects of the person we once were while simultaneously accommodating the uncertainty of the person we must now become (Algar, 2014). The women used liminality to identify the ambiguous spaces while living with breast cancer. Many of the participants talked about trying to maintain a normal life while struggling with all the changes of their emotional and physical bodies that were no longer normal and would never be normal.

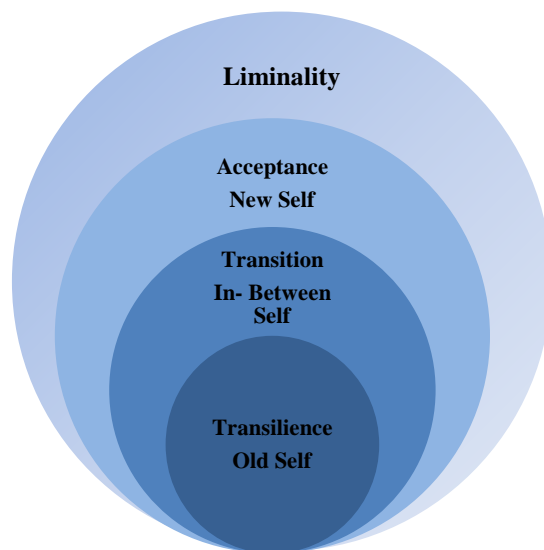
Studying various individual attributes people demonstrate during a health challenge, such as breast cancer or any chronic disease, will increase the health care professions’ understanding and assessment of overall health patterns leading new insights into research, practice, and education (Polk, 1997). There are a multitude of factors that can make a person adapt better to adversity than others. Bromley (2005) suggests in his research that the dynamics of resiliency in the narrative has come to be defined as a complex interaction between the person and his or her environment that is highly

contextual in nature. The list of protective or mitigating factors is long, and the interactive effects are in some cases complex. Some studies have taken a contextual or case-by-case approach, which identifies salient variables within specific sets of circumstances (Masten, 2001). In exploring the concept of liminality in the field of nursing may provide a better way to facilitate outcomes for this patient population.

Liminality within the context of illness is similar in other chronic illnesses because it can promote better strategies for coping and adapting with a life-long illness. Each participant's story vacillated back and forth about facing sudden change and facing uncertainty while transitioning and moving forward and accepting cancer. As Esther described the liminal place of waiting: "Every three or four months I do get anxious I bring a book and I get there early; I start to get a little anxious. Life should not be spent that way." The current investigation explores the lived experience in cancer survivorship while in the surveillance phase of recovery. Understanding the liminal pathways in facing breast cancer may cultivate new ways of adjusting, redirecting, and building resiliency in cancer survivorship. There are no set attributes of behavior that lend to a solid definition of resilience or how people ascertain acceptance of a disease; however, studying different breast cancer populations will enable nurse researchers to shed light on recovery paradigms to enhance physical and mental well-being in those suffering from inadequate coping skills. The process and the individual identifying factors by which resiliency traits develop represent ongoing in research to examine what constitutes resilience in all age groups (Atkinson, Martin, & Rankin, 2009).

The following inter-connecting circles represent the interplay of attributes in the participants of this study, which are essential in building a bridge of transilience,

transition, and acceptance, and which facilitate moving forward in life while living with cancer. Each participant was cognizant of their renewed sense of self and the perception of this adversarial life event. The themes created a dynamic flow in understanding liminality as a pathway to healing and allowed the participants to create a new self and harness change in order to move forward in life.



*Figure 3.* Overlapping themes: Liminality: Thresholds of moving forward in surveillance phase of recovery (Amado, 2015).

### **Chapter Summary**

The narrative stories in this study provided the researcher with rich and meaningful descriptions and increased understanding of what it is like to live with breast cancer and the life experience of participants within the context of their illness. It outlined a genuine descriptive method by avoiding making assumptions about the



experience of the illness and avoided causal questions about breast cancer. The researcher attempted to illuminate the meaning spoken by these women in their everyday lived experiences throughout their journey. This inquiry was guided by an Manen's (1990) hermeneutical phenomenological method of inquiry and sought to understand his four existentials of temporality, spatiality, corporeality, and relationality as it pertained to the themes of transilience, transition, and acceptance. Many of the participants accepted the fact that breast cancer may never go away and is forever ingrained into their being. The future while living with breast cancer and accepting the reality of constantly oscillating between letting go of the old self; transilience in fear and hope; transition in fighting and adjusting; and finally, gratitude and healing in acceptance. These women, while facing a major health challenge, met adversity head on with unwavering courage and faith. Each participant exuded a quiet strength in finding a way through a crisis and was determined not to be a victim of breast cancer. By examination of the core themes, transilience, transition, and acceptance, this study ascertained the usefulness of liminality as a concept for understanding the lived experience of breast cancer survivors. By reviewing the liminal lived experience at all the stages in the breast cancer trajectory may facilitate a better understanding of this phenomenon of surveillance. It provided a deeper understanding into the life world of the lived experience of women with breast cancer in the waiting phase of surveillance, the "betwixt" and "between" time, and created a new way of understanding the experience of one's life being disrupted through illness and what it means in relation to long-term survivorship.

## **CHAPTER FIVE**

### **DISCUSSION AND CONCLUSION OF THE INQUIRY**

The purpose of this phenomenological study was to explore the lived experience of women with breast cancer during the surveillance phase of recovery. The significance and the meaning of this study were explored to reflect the dimensions of the women's realities as it pertained to their life post-diagnosis and treatment of breast cancer. The approach of phenomenology provides a unique method to explore the experience of illness. It is an authentic and genuine way to reflect on one's life through narrative discourse. Stories remain an indispensable source for understanding ourselves and others and human action as situated in temporal (Benner, 1994). This study created a deeper meaning in understanding breast cancer survivors and their health challenges and how resiliency is built to endure life's uncertainties while living with breast cancer. An interpretative analysis of the themes that emerged from the study will be presented along with published literature that complements the findings of the study. A discussion of the relationship between the findings of the study and a brief description of the essence of liminality will be analyzed. The implications to nursing education, practice, research, and public policy along with limitations of this study will also be discussed.

#### **Exploration and the Meaning of the Study**

The guiding question for this qualitative hermeneutic phenomenological inquiry was, "What is the lived experience of women with breast cancer in the surveillance phase of recovery?" This study began as a personal quest to investigate the needs of women suffering from breast cancer after they are finished with acute treatment and are left to

manage their disease for the rest of their lives. This specific study focused on the phase after acute treatment is finished and all the participants are settling in with living with a chronic disease. The health outcomes varied in the participants studied. It is a time of uncertainty for many, and it is a time where making sense of a chronic illness is pinnacle to recovery. The researcher was able to discover deeper meaning and pure essences of this phenomenon by listening to the stories of the women. By listening to the words spoken and examining the text, the researcher found common threads with each woman's lived experience that illuminated the overarching essence of liminal pathways of surveillance. The researcher was able to consciously listen to each interview and carefully read and re-read texts, thus ensuring that she had accurately described the participant's life story with recounting the life events as they unfolded from the participant's perspective. When the language became repetitive during data collection, the researcher realized she had reached saturation.

Bracketing allows the researcher to analyze data without confirming her presuppositions and enabled the researcher to have the story become truly authentic from the participant's life world. The researcher transcribed each audiotaped interview. Listening to the narrative, reading, and re-reading together with the reflective journal helped the researcher to understand the emergence of the themes and the underlying essence of a liminal pathway to healing. The stories of the women gave voice to this ambiguous time while on a liminal pathway through surveillance and survivorship.

### **Interpretative Analysis of the Findings**

#### **Transilience: Sudden Change**

The definition of transilience is noted as an abrupt change or variation (Merriam-Webster, 2005) and also an event usually caused by crisis. The current research investigation of surveillance in breast cancer survivorship manifested in various ways in the participants. Transilience is focused on transformation and the processes we facilitate are thus designed to produce real and sustainable change in regards to adapting to breast cancer. The core motivation is to contribute to positive transformation in people's lives while living with a chronic illness, which is at the heart of the beginning of the liminal pathway. Transilience can be understood as leaping or passing across the unknown from a wellness state to a state of illness and to be somehow transformed by the experience. This sudden change in a person's lived time, temporality, as it pertains to a cancer diagnosis is a time of letting go of the old self both emotionally and physically.

The concept of liminality creates a pathway to better understand illness, in particular cancer and sudden changes in their lives. The surveillance time is the time participants experience coming to terms with diagnostic tests, treatment, side effects, and the reality of facing an uncertain future. Transilience is a disruption of temporality, spatiality, corporeality, and relationality in reference to van Manen's (199) existentials. However perception of time and body were mentioned frequently in the participants' narratives while reflecting on their disease process. The liminal pathway in living with breast cancer is a dynamic process from the time of diagnosis throughout treatment and becoming a long-term survivor. It is a story that no one can tell except for the participant. At times the narrative reflected that the sudden diagnosis of cancer caught

them off guard. Suddenly illness arrives, uninvited, unexplained. One finds oneself caught between life and death, light and dark, banished to an unknown place between night and day. The arrival of illness interrupts the cycle of life (Carlick & Biley, 2004).

A study done by Boehmke & Dickerson (2006), utilizing a qualitative Heideggerian hermeneutic method to gain a better understanding of the common meanings and shared experiences that women encounter after a diagnosis of breast cancer, highlighted needs of survivorship and support post treatment. Purposive, convenience sampling recruited 30 women with the mean age of being 47 years old and focused on secondary analysis on tape-recorded interviews of women receiving their last cycle of chemotherapy. Narratives were interpreted using the seven-stage hermeneutic process, including life experiences, shared meanings, and perceptions. Four themes emerged: Changing Health Overnight, Erasing of a Former Self, Appraising of Illness, and Approaching the Future Now What? The constitutive pattern was transitioning from health to illness. The findings warranted women experience a precipitous change in their lives after a diagnosis of breast cancer. How they mentally and emotionally approached diagnosis and treatment affected their symptom experience and outcomes. This study provides oncology nurses with the awareness that beyond physical symptoms, women experience profound and precipitous emotional transformation following a diagnosis of breast cancer. It gives meaning to the devastation and symptom distress women experience that may be lessened if they are given adequate information and support. Women in the study who approached diagnosis and treatment more positively better incorporated the breast cancer process into their lives and better managed the side effects of treatment (Boehmke & Dickerson, 2006).

Researchers describe accepting change as a type of continual process as “things fall into place” and observed that ill and dying patients who had experienced healing were “quietly accepting it with the heart ” (Egnew, p.252005). The participants in this study had to learn to let go of being a healthy person and accept living in the dynamic ebb and flow of wellness and illness simultaneously. Each woman came to the realization that this waiting time, liminality, after diagnosis is an ambiguous, stressful place to be. According to anthropologist S. Lochlann Jain, the prognosis of cancer activates terror, and the shock of having cancer and living in prognosis severs the idea of a timeline. The diagnosis of cancer deals an initial blow, a shock to mind and body-a traumatic event. At the moment of diagnosis, when all you have is this signifier cancer, you are, in that instant a heartbeat away from prognosis (Jain, 2007). The place and time of surveillance and recovery seems to be a place of constant waiting, which appeared to create a common thread of distress in the participant’s narratives. An abrupt change in their life timeline was beyond their control. This liminal space of transience initiates a change in the chronicity of their life world.

A recent study on time and illness was done by van Laarhoven, Schilderman, Verhagen, and Prins (2011). The study demonstrated the effect of time perception of cancer patients. Time perception may be an important factor influencing distress of cancer patients. However, no comparative studies have been performed for cancer patients without evidence of active disease and advanced cancer patients in the palliative, end-of-life-care setting. A descriptive research design was used. Ninety-six disease-free and 63 advanced cancer patients filled out Cottle's Circle Test to assess time coherence and time dominance, Cottle’s Line Test to assess temporal extension and Bayes' question

on speed of time, the European Organisation for Research-and-Treatment of Cancer QOL-Questionnaire version 2.0, Beck's Depression Inventory for primary care, and Beck's Hopelessness Scale (van Laarhoven et al., 2011). The results showed that in patients without evidence of disease, future dominance was most often observed, whereas in advanced cancer patients, the present was the dominant time segment. In both groups, a focus on the past was associated with distress. In contrast with patients without evidence of disease, advanced cancer patient's perceived time as moving slowly, and this was correlated with increased distress.

There are similarities in the prior study with the present study in regards to the perception of time within the context of illness. This sudden change in the participants' lives enabled the women to reflect upon the past while living in the present, and transform to a new self, a forever changed self, in the present. The surveillance time is a dynamic time as one manages their illness while learning to accept change and transition. The emphasis of this is focused upon the individual's personal account of breast cancer through their personal narrative. In reviewing the lived experience, a liminal pathway emerged from the themes that emphasized rather than minimized the personal significance of breast cancer in each participant's journey. The women in this study viewed time as a valuable commodity as evidenced by the participants' narratives.

Each participant had a personal way of tracking time as it related to their disease but have learned to settle into the wait: waiting for the next oncologists appointment, improved health, possible recurrence, or even negative test results, hence the liminal phase. The liminal pathway consists of transilience, assimilating, and transitioning into a new way of being in the world, allowing the chaos from cancer to situate itself into one's

life. The memory of the disease for some may have dimmed but each participant had a greater appreciation for living even when regressing about the journey. The dynamic interplay between letting go of the healthy self and accepting the illness cultivates a path that seem to transform the participants old self into a cancer survivor. While facing uncertainty and transitioning through a chronic disease, many of the participants maintained their everyday activities and responsibilities while struggling with the knowledge of having cancer. The way the participants remembered past events of cancer built a bridge to the present state of living with cancer. Memories and markers in time are key elements of the way we experience time (Hammond, 2013). Time is thereby interpreted as a modification of presence. We call “past” what is no longer present and “future” what is not yet present (Alweiss, 2002). Many of the participants understood the importance of traversing the bumpy ground of breast cancer and began to let go and transition to a new place. Some of the participants transitioned better than others through the sudden, unexpected event of a diagnosis of breast cancer. Again, the liminal place is like a tunnel between wellness and illness. It is a time of uncertainty and navigating the unknown.

The women in this phase of healing used both prospective and retrospective ways to gauge time and its passing in order to adapt to a chronic health challenge. The path to transition started with most of the participants by entering the life world of the ill with the hope of finding their way through this dark time. The woman at the beginning demonstrated the importance of looking back and telling their story, which reduced their stress about cancer. Many of the participants shared their stories of it becoming easier to talk about their breast cancer. According to the rites of passage (liminality) framework



proposed by van Gennep (1961), any transition begins with a pre-liminal period of separation from ordinary or previous social life, followed by a liminal period of undefined duration, and concludes with a post-liminal period characterized by a re-aggregation to a new state of being. The liminal period is structurally and physically invisible, and the liminal persona is a transitional being, in the process of being initiated into a very different state of life.

During the liminal time, the individual exists in a state in which the past is left behind but the future state has yet to emerge (Turner, 1994). The pre-liminal as mentioned above is the time in surveillance where the woman is separated from her existing health status influenced by transience, followed by an adjustment phase of transition in the liminal pathway, and concluding with a post-liminal stage that manifests in maintaining and adjusting to cancer. The sudden change for all of the participants started as being a normal healthy woman then gradually transition to letting go and move into the uncertainty of treatment. It seems to be a slow but continual process. The word process refers to the dynamic nature of a transition experience. Furthermore, the process is ongoing, and more than one type of transition can occur simultaneously while transitioning through a chronic illness (Meleis, 2010).

A recent study done on breast cancer survivors and the stories of change and meaning by Gerhart, Reynolds, Britton, and Kruse (2010) addresses the importance of qualitative investigation of experiences of eight breast cancer survivors. In this study, all of the survivors reported they had changed physically, emotionally, and spiritually during their breast cancer, and now viewed life in terms of before and after regarding an abrupt change. The method of the study was a phenomenological case study examination of

change and meaning making during their experience the findings supported posttraumatic growth as a part of survivorship for the participants. The participants' ages ranged from 28 to 80 years old at diagnosis. The study focused on the perspective of the participant as shared in the narrative by the survivor. The method enabled the participant to reconstruct their story via her breast cancer experience, within the social contacts, while making sense of it all. The sudden disruption of their identity and the need to identify what they needed during treatment was a major finding in the research (Gerhart et.al, 2010). The goal of the analysis of this study was to identify themes that would enhance the understanding of breast cancer survivorship. There were common themes in this study of changing life priorities, altered relationships, and desires to help others. These are similar and supportive findings to the present study regarding the surveillance phase of recovery and liminal pathways to healing. Research is needed to define and clarify the nature of survivorship while in surveillance over time.

Personal context incorporates cancer survivorship and personal characteristics across biological, psychological, and social domains. The adaptation process involves a specific cognitive mechanism of change, where the ongoing appraisal of goals and world assumptions occur in the context of the cancer survivor's personal memories and sense of self (Naus, Ishler, Parrott, & Kovacs, 2009). A model of cancer as a chronic illness is proposed as a new direction for quality of life research. In the Cancer Survivor Adaptation (CSA) model, adjustment to cancer survivorship is a life-long process involving three interacting themes reflected in the study done by Naus and associates. Pathophysiological distortions in human timing and time perception interest to both basic and clinical researchers for several reasons that could improve understanding the psycho-

social element of an illness such as breast cancer could improve upon misconceptions of this ever-growing population of survivors (Naus et al., 2009).

The need to study life-threatening illness such as breast cancer produces complex experiences that may not be easily understood in the traditional sense in this rapidly growing population: survivors. A study done by Adamson et al. (2004) studied memory in chronic illnesses, examining the pain and health status of survivors of a critical and chronic illness. The aims of the qualitative aspect of the study were to examine the participants' memories of acute illness and hospitalization at six months post-discharge and to explore the impact of the illness experience on their recovery. Purposive sampling was used to enable rich descriptions of the experience of recovery from those patients best able to articulate their experiences. The findings focused on life experience. The three themes that emerged from the data were the recollections, reactions, and comfort or discomfort (Adamson et al., 2004). In this specific study, some patients recollected and accepted the illness, some had increased anxiety and chose to forget the whole initial experience, and lastly the results showed evidence of comfort or a state of discomfort. Nevertheless, all of the participants demonstrated some form of residual physical or psychological problem from their chronic health condition. The findings concur with better integration of services and continued support is required for survivors of a chronic illness up to and beyond six months (Adamson et al., 2004). The need for continual support in the surveillance phase of recovery indicates the need to individualize a chronic illness such as breast cancer in order to rehabilitate and transition the patient to an improved quality of life. Most of the present research in regards to cancer perspectives in regards to chronic illness is solely based on periods of exacerbation and remission of

distressing symptoms. Many health care professionals are caught in the tradition of rehabilitating people with chronic illness by assisting them to accept the limitation imposed by their disease. Such an approach might be counterproductive (Paterson, 2001).

As the participants begin to integrate cancer into their lives and come to terms with the initial shock of the diagnosis, a new liminal pathway arises; transition. The relevance of reflecting back in time about their illness and treatment offered a perspective of self-interpreted acceptance to sudden change (transilience) in relation to the individual's ability to move forward in life. The subjective sense of time is fundamental to our psychology and conceptions of reality and is part of the intellectual structure by which we make sense of the temporal course of events in our lives (Ricoeur, 1984). Vacillating between wellness and illness is a constant denominator of living with breast cancer. Frankl (2006) posits that the meaning in life is to be found in what he calls "the self-transcendence of human existence" (p.110) a discourse, which is often associated with time and a progression toward spirituality in order to make it through adversity. The women in this study shared similar characteristics to Frankl's search for meaning through a similar technique of sharing stories of painful memories increasing spirituality, social connectedness, and holistic methods of healing. Journaling was done by many of the participants to assist in understanding the implications coupled with living with cancer.

Logotherapy may not all be retrospective but focuses on the future life events, by the meanings to be fulfilled by the patient in the future (Frankl, 2006). Through sharing their stories the women found solace in transcending time into something to treasure and not something to fill. Facing a stressful event in life and the accuracy of the actual

adaptation to the event were similar in nature and allowed the participants to create a pathway and enable a transition bridge between wellness and illness while living with breast cancer.

**Transition: The In-between Time: Limbo**

Transition is the process or a period of changing from one state or condition to another and is the place where the participant faces the uncertainty of breast cancer while struggling to maintain. Transition occurs as a result of illness and changes in health status, people who experience life-threatening illnesses pass through a transition but there is still much that is unknown about the meanings that are constructed out of these events. By developing and looking at transition it is likely we will be able to build and set priorities in individual illness cases (Melies, 2010). The transition phase is the place where the participant starts to adjust to a world of illness, which manifested in staying positive with work, a social network, and alternative modes of healing in order to manage the disease process, which is the step between transience and acceptance. The participants in this phase are not back to normal, which is a place of adjustment of lived time, lived body, live space, and lived human relations. For many of the participants it was a time of living in limbo. As Nicole shared:

We talked about the surveillance in the group and that's exactly perfect. And that's where I am at. If they are telling me to go every week or every month I'm good with that, surveillance me I want to be sure I'm under close watch. When all of this started coming about it was rattling my cage, and I said you need to make some life changes because here today, gone tomorrow. I want to live to be 100 years old. I have to be here for my kids.

This study explored a new way to look at memory in the trajectory of the illness. Many of the participants hoped that the cancer would prove to be treatable and they would be healed or stay in remission. There appeared to be a common undertone while living in limbo. The transition time for the participants was a time of waiting for negative or positive test results or possibly a discovery of a new symptom. Life kept going but the constant waiting for test results triggered emotions of doubt and fear in many of the women. Transition in this phase of surveillance phase is ambiguous. It is a place of uncertainty for many that are facing a chronic illness.

Much of the time the participants reached back in their memory in order to tell their story of illness. The story became clearer the more the women retold the events of living with cancer. A study by Jacobi and Macleod (2011) demonstrated the role of memory being central to who we are at in the trajectory of illness. This poem by Graves (2014) reflects the liminal place of transition between health and illness and facing the uncertainty of life:

**Memory to Memory**

Memory to memory

Word to word

Face to face

All taken in with a deep breath

Absorbed in the mind

Like water to a sponge

Taking in every last bit

Those things are what get us from place to place.

What opens the door to new adventures  
New experiences  
Whether they are good or bad  
Though each needs to be handled carefully  
Each of them is more delicate than a newborn baby.  
At first you never know the potential each one has  
Some lead to destruction  
Others to beauty  
But all of them shape us  
Make us into who we are  
Form our lives  
Until that last deep breath is taken  
And we Exhale

In this phenomenological study, participants shared painful memories and times of frustration with what was happening in the present in terms of their illness. The findings demonstrated that all the participants had a connection to a sense of being, such as pain, joy, sorrow, and feelings of grief and satisfaction. The findings were relevant and were not simply dependent on events in life, but on the ways in which they events were remembered. Many of the participants in this specific study mirrored the same feelings that form the foundation of their self-made resiliency (Jacobi & Macleod, 2011). It speaks of how a person recalls and reminisces about something painful that has happened to them in the past and the way it prepares one for the future. Nouwen (1976)

reflects on the expression “reculer pour mieux sauter,” meaning “to step back in order to jump farther.”

To reiterate, each woman vacillated back and forth between the themes of transience, transition, and acceptance while sharing their stories. Many of the participants, despite their stage of cancer, resonated a keen awareness of confronting breast cancer and reducing fears by sharing their lived experience of breast cancer from beginning to the present. In many of the participants’ narratives it was a time where they began to take charge over their illness and not become their illness. Sources of uncertainty in cancer survivorship are many. They have medical uncertainties such as diagnostic ambiguity, unclear staging of the disease itself, ambiguous symptoms, and treatment complexities. Along with unpredictable prognoses, there is an undetermined need for continued care throughout the trajectory of this disease process. There are also personal sources of uncertainty such as conflict identity, physical changes, and possible unpredictable employment consequences, as well as many others. Social sources of uncertainty may be unpredictable interactions, changed friendships, and ambiguity of all relationships (Miller, 2012). Sharing their stories and addressing the stigma that cancer sometimes represents diminished some of the distress associated with living in limbo between sickness and health.

People who are able to share their stories may be less likely to become clinically depressed. Smith and Liehr (2003) posit that the human story is a health story in the broadest sense. It is a recounting of one’s current life situation to clarify present meaning in relation to the past with an eye towards the future. In the process of telling and hearing stories, the person often comes to new insights and deeper understandings of themselves



because stories include not only events but also interpretations of the events of particular lives. In some instances stories may also amend us when we are broken (Smith & Liehr, 2003). It was difficult at times to differentiate between each theme while examining the texts. Each of the themes blends with each other to create a liminal pathway through the chronic uncertainty while under surveillance. Long-term cancer survivorship is steadily increasing and understanding individual's experiences throughout cancer survivorship is essential (Miller, 2012).

A quantitative, correlational study done by Brown, Levy, Rosberger, and Edgar (2003), which examined 205 men and women cancer patients, demonstrated a direct link between depression and survival (up to ten years) among the analysis of data. The study tested the predictive role of psychological distress. It measured various range of emotional and cognitive factors in early post-diagnosis, four months to fifteen months after diagnosis, which were used to predict survival time up to ten years. The conclusion showed the importance of depressive symptoms and mediating or reducing them and the importance for further research in the recovery phase of cancer (Brown et al., 2003). Exploring alternative ways to enhance resiliency and coping is vital to a good prognosis and quality of life. Through a narrative authentic discourse, the patient's story unfolds as they remember it. The recollection of the shock of diagnosis, treatments, and recovery had similarities in the narratives that demonstrated a propensity to create meaning out of such a malady.

All of the women in this study continue to receive some type of medical intervention whether it be oral anti-cancer drugs, tumor markers every 12 -16 weeks, or frequent body scans to check the dormancy or activity of the disease. Each one is under

constant surveillance by a physician. Clearly, the recovery process for survivors of a chronic illness is an important but under-researched area, particularly from a qualitative perspective.

A retrospective and prospective exploration of the impact of the illness experience is emerging in recent literature about long-term survivorship and holistic pathways for living with a chronic illness. A study done by Kriegel, Myers, Befort, Krebill, and Klemp (2014) conducted a study of the lived experience of women with metastatic breast cancer (MBC). The aim of this study was to further explore the lived experiences of women with MBC to inform the development of interventions to enhance survivorship care for women with advanced disease. Four semi-structured focus groups were conducted with women with MBC, and the data was analyzed using qualitative content analysis. Participants described the challenges of living with uncertainty, as a result of a lack of information regarding treatment options and symptom management, and a sense of the unknown related to prognosis and survival. Of major concern were changes in role functioning, altered relationships, and self-image. The findings of the study demonstrated women with metastatic breast cancer must cope with dramatic changes in all aspects of their lives. Clinicians should tailor survivorship care and evidence-based interventions to individuals' concerns with changes in role functioning, fatigue, relationships, and self-image. A multidisciplinary approach should be used to address practical and existential concerns focused on improving quality of life (Kriegel, et al., 2014).

Understanding the need for continual care in breast cancer patients throughout their remission, checkups, and tests is an area of uncertainty and fear. Sometimes breast

cancer is unpredictable in regards to the prognosis. As NeeNee shared, “I go for mammograms and I go for ultrasounds and I really don’t like the person that I am during that time. So I panic about that. I go see the doctor but I’m not ready to let go.” The memory of being diagnosed with cancer was re-experienced as the participant’s added new information as they reconstructed the experience. By reconstructing the memory of cancer, this study share similarities in demonstrating the importance of dealing with sudden change and transitioning to a new future.

As Hammond (2013) explains, when defining time and memory of an event the neural signatures of remembering a past event and imagining the future are remarkably alike when the perception of time is considered. The present study demonstrated the importance of gathering the patient’s lived experience of surviving an illness and continuity of care. Listening to the women’s stories allows for further insight into their life worlds as it pertains to their illness and moving forward. The aim of phenomenology is to transform lived experience into textual expression of its essence. The text then becomes a re-living and reflective appropriation of something meaningful (van Manen, 1990). As Laura 63 poignantly stated, “Because of lingering side effects from the chemo and radiation my quality of life has improved but I think it’s because I’m working; but maybe it’s improving because time is just passing.”

A phenomenological study by Stoval (2012), utilizing a selective sample of one hundred breast cancer survivors post-treatment, explored the expectations of breast cancer survivors and the psychological aspects affecting living with the disease. The findings demonstrated that there appears to be little knowledge from the health care providers, especially oncology nurses, about caring for breast cancer patients and the

breast cancer survivor's needs after the patient is finished with acute care treatment. The patient is under constant surveillance, with appointments usually spanning over a twelve week period, which includes tumor markers every twelve weeks and oral chemotherapeutic agents such as Tamoxifen or Herceptin, depending upon prognostic indicators (Stoval, 2012). This study was premised upon psychological causal factors such as coping and adaptation and was not done as a hermeneutical approach of the lived experience. Many of the studies about breast cancer and coping are done from cognitive and developmental approaches that offer a useful framework for making decisions about prevention and clinical procedures with breast cancer women, which may benefit clinical outcomes. However, it lacks insight into the participant's lived experience of illness in the surveillance phase of recovery and long-term survivorship.

The constant state of living in limbo with appointments, labs, and scans created anxiety even though many of the participants are in remission. Many of the women experienced an impending sense of doom each and every time they waited for the next appointment. This place is a liminal path of oscillating between wellness and illness. There are complex and synergistic relations in breast cancer survivors in the initial phases of the disease. Positive aspects include seeking a sense of wholeness after a life-changing experience, having a life that is unique to the individual's experience, contrasting between the focus on the moment and the focus on the future, changing values and priorities, receiving help from others, and helping others, which increases appreciation for life (Farren, 2010). The participants all arrived at accepting the diagnosis and began to realize life is changed forever. All the women wanted a better quality of life after the diagnosis of cancer. However, some women shared the fear of

dying throughout the narratives. It was part of the process of transitioning and accepting the illness and moving forward. As Esther shared, “I don’t want to die now. I know death is a part of living, I sort of look at it that way.” The participants, while living with constant uncertainty, cultivated positive ways to adapt.

### **Acceptance: Moving Forward**

#### **Positivity in the Liminal Pathway**

Many of the participants in this study discussed positive outcomes as a result of their experience with breast cancer. Bonanno (2004) suggests that self-enhancement or an overly positive bias about oneself is one pathway to resiliency under stress. Resilient people cope with stress better because they use particular skills and abilities in stressful situations. Positive thinking does not have a common accepted meaning. Positive thinking, like hope and optimism, is a term that covers a range of concepts and ideas (Norem & Chang, 2002). Due to its status as a taken-for-granted of modern thinking and pop psychology the definitions of positive thinking are usually general and non-specific. A study done by Horgan, Holcombe, and Salmon (2010), utilizing a grounded theory method, explored the process whereby positive emotional changes were studied in 20 women that were diagnosed with breast cancer. The average age of the women was 53 years old. The results exemplified most of the women experienced several positive changes as a result of their breast cancer. Analysis suggested that changed priorities in life and increased empathy for others emerge from the patient’s reflections upon the suffering they endured during their illness. Factors promoting reflections included acceptance of breast cancer, ending treatments, and communication from others. Findings extended that current trauma processing theories can for the timing and the

design of clinical intervention to improve adjustment to breast cancer. Some researchers have previously discussed these changes as self-transcendence that is fundamentally different from before diagnosis (Horgan et al., 2010).

The foundational concepts of liminality manifest differently in the acceptance phase and are non-linear and dynamic. The blending between each theme in developing positive coping mechanisms and resiliency is evidenced by the participants' positivity, social and spiritual connectedness, and holistic ways of healing creating a path for making meaning out of the unknown. Many of the participants, while living in limbo, utilized alternative modes of healing such as prayer, journaling, healing touch, and art to facilitate healing. Research on positive thinking and staying active while fighting cancer focuses on two broad hypotheses. Medical research has purported that it increases the likelihood of a good outcome, and social research suggests that it enables people to cope better with their experience of the illness and its treatment (McGrath, Montgomery, White, & Kerridge, 2006). "I really try to look at the positive. I am much more aware over all. I look at life as a gift it made me a stronger person because I know I can get through this." Shares Jackie.

### **Spiritual and Social Connectedness in the Liminal Pathway**

The participants' faith manifested in a renewed sense of spirituality and social connectedness. The need for spiritual and social relationships appeared of utmost importance in many of the narratives. NeeNee shared, "I remember going to my mom and my mom and I going to church the next day after I was diagnosed. I remember going to church and saying okay, alright God I'll do chemo, I'll do it but..." Spirituality for most of the participants was an important factor on the liminal path to healing. The

participants varied in religious affiliations, yet the common bond of a belief in something greater gave each participant unwavering faith in their recovery. Religion as a concept is based on the fact that it is associated with the teachings and rituals of various beliefs. It is not obvious that spirituality includes specific beliefs about a higher power, but may entail an expression of philosophically designed beliefs focused around art, nature, or music. It may also involve a special relationship surrounding loved ones or significant others (Wilber, 2008). Spirituality supports the idea of individualism and uniqueness within the context of worldviews. Spirituality may play an important role in how an individual interprets, develops, or comprehends an event such as an illness, and more importantly, how one chooses to cope with a circumstance (O' Neill, 1998). As Mari shared:

I have learned to lean on the Lord more. And I put all of this at his feet. I still think about it once in a while but you really try to put it behind you. He's going to take care of this or at least give you help to handle it, to get through this.

Researchers Finnell and Jezewski (2007) conducted a concept analysis, guided by Walker and Avant's methodology, to examine how spirituality has been used to clarify the meaning of spirituality by discovering this concept's critical attributes of spirituality. The concept analysis findings revealed that spirituality was defined by four major themes: spirituality is a religious set of beliefs and values, it gives life meaning and connection to others, it can be a nonreligious system, and it is explained as a transcendental phenomenon (Finnell & Jezewski, 2007). Sometimes, it is the patient and other times it is the patient's family members that reach for spiritual or religious guidance, even though they may be distant or angry at this belief system (Lewis &

Peterson, 2013). Spirituality throughout time is considered believing in something greater than ourselves. The connection with van Manen's (1990) existentials of the lived experience becomes clear as explained by Pesut (2008):

We exist simultaneously between our life worlds, a time between times so to speak. We exist in a physical space, bound by time and space for the present but we are aware of the connectedness of it all. Moreover if a person believes that this world is a preparatory time for the next when dealing with a chronic illness, then physical existence becomes important as much as the spiritual.

With regard to this study and the four existentials of temporality, spatiality, corporeality, and relationality, the participants shared how they experience time, temporality, the embodiment of the illness, corporeality, and lived relations, relationality. As Jackie shared:

I can look back over my journey and embrace it. I definitely consider myself spiritual. It comes out when I'm here walking in the garden. I am not a big prayer person but in terms of spirituality, my parents are both gone, I spoke to them a lot so to me it wasn't really talking to God it was talking to my folks who I was very close to. It gave me great comfort.

The overlapping of the themes demonstrated a dynamic flow of becoming a changed person in the individuals' cancer timeline. The ambiguity and the uncertainty of cancer seem to propel the participants toward aesthetics and holistic ways of healing. Many of the participants shared that they prayed or meditated in some capacity to get through the day: "I do pray by myself on the beach I do, I am of Jewish faith you know, I



go to temple, I am not a fanatic but I do talk to him. I thank God and I'm glad I'm okay," explained Sherry.

There are strong relationships between spirituality and coping that come from the fact that many individuals search for spiritual guidance during stressful life events, using spiritual practice as supports means (Krok, 2008). An exemplar study by Krok (2008) reflecting coping during stressful life events was done as a quantitative study dealing with spirituality and coping styles. The study chose 208 participants and rated them on a questionnaire; there were 112 females and 96 males from various backgrounds. The study utilized the coping inventory stress situation tool (CISS) and the self-description of spirituality tool (SQS). Through t-tests and a multiple regression approach, results with the significance factor set at  $p < 0.001$ , the concept of spirituality and the concept of harmony, were most significant in the findings in recognition that spirituality dimensions were vital to both sexes in coping processes (Krok, 2008). Even though this study quantified spirituality, it is in alignment with the present findings of this study that the participants expressed in their narratives. The narratives of the participants revealed the individual need for spirituality in order to transcend their illness.

Another pilot study done by Gockel (2009) used a narrative method to examine the experience of 12 participants who self-identified as drawing on spirituality for healing. Participants described a 7-step process characterized by (a) openness, (b) shifting to a spiritual perspective, (c) going within, (d) connecting with the sacred, (e) undoing patterns, (f) setting healing intentions, and (g) following their inner guidance to transform experiences of mental and physical illness into experiences of healing. Participants emphasized the role of spirituality in reconstructing positive meanings in the

face of crisis and deconstructing patterns of thought, feeling, behavior, and experience associated with illness (Gockel, 2009). There are many simultaneous concepts that build upon spirituality and enable the concept to evolve with each subsequent inquiry in the research arena. Coping and quality of life with the basis of spiritual factors gave many of the participants the ability to find meaning, accept illness, and even accept their own mortality. Sherry expressed, "I think I've grown more as a Christian. Maybe that's the purpose to become more godlike and honorable to strengthen me and not make me to be so gullible." The importance of their faith was important to survival at different times along their path to recovery.

Spirituality and positive thinking, particularly in a serious illness such as breast cancer, had an effect on minimizing their stress about living with cancer. However, with staying positive, social and spiritual connectedness were also evident in the narratives. Many of the women in this study were staunch believers of the importance of social connectedness and were presently active in cancer support groups. Lisette said:

I go to the support group once a month. Sometimes twice. I go to group, hear the women and their stories. It's like a crapshoot (talking about the recurrence of cancer) I get comfort and solace from the support group. It's hard to talk to somebody who hasn't gone through this they just don't get it having gone through it, they don't know the subtleties of it.

Research findings in mental health consistently identify the importance of a social network. It is common knowledge that it is important to have contact with others to decrease any social isolation. A diagnosis of cancer for many of the women had an impact on their social ties initially. The importance of friends and family truly affected

how some of the women adapted better than others. Many survivors expect for their lives and relationships to return to the way they were and to move forward in life, as if breast cancer was a benign illness with no aftermath (Rancour, 2008). Many of the participants found comfort and solace in the breast cancer support groups and still attend to this very day.

A quantitative study done by Cowen, Wyman, Kim, Fagen, and Magnus (1997) about stress affected and stress resilience revealed the individual's perception of the quality of relationships, their number, and their observable characteristics are associated directly to good outcomes (Cowen et al., 1997). The results are presented in three sections: (1) comparisons of resilient and stress-affected groups on interview variables; (2) a discriminant function analysis to identify the optimal combination of variables differentiating the groups; and (3) test of a mediational model to account for interrelationships among caregiving environment variables (Cowen, et al., 1997 ). In this study, resilience reflects a mastery of age-salient objectives, in the face of substantial adversity, by drawing on internal and external resources that enhance processes of adaptation specific to each developmental stage (Cowen, et al., 1997). This study is premised upon adaptability and is a comprehensive view of the importance of positive social support in order to gain resilience in facing adversity at any age. It draws upon the importance of accepting a crisis, managing it as well as possible and resolve to move forward.

Comment [JA2]: This is unclear.

In transitioning between the initial diagnosis, treatments, and living with a new reality, relationships in this study proved to be of great comfort. The women spoke of how they coped with living with breast cancer while being in a state of constant flux.

The change in the participants was evident physically (such as body image disturbances due to mastectomy and /or radiation) and emotionally, as in the constant stress of living in limbo and waiting for tumor marker results and labs every 12 to 16 weeks. The participants became increasingly aware of making meaning out of their sickness. Phenomenology allows for reinterpretation as new meaning, or fuller meaning, or renewed meaning, it is precisely what we phenomenologists are after, a fresh look at existence (Crotty, 1998). After facing an ambiguous, unpredictable prognosis of breast cancer, the participants re-mapped their future. The participants went back to the future, returning to the old self or a better version of themselves through exercise, improved nutrition, journaling, prayer, and other holistic modes of healing. As Susan shared, “I do yoga. I was doing it before so maybe that may help me at some point but I go to class on Monday evenings, I try to do it every day. I try to meditate but I can’t, I try but I just can’t.”

Comment [JA3]: Is this a quotation?

### **Meaning in the Liminal Pathway**

Making meaning out of the disease was imperative for each one of the participants’ survivals. The women spoke of a greater need for a sense of purpose after the diagnosis. Many of the participants are in remission presently and will be actively in surveillance for an unknown amount of time. For all the participants, placing meaning was in the forefront of their waking thoughts every day. Time became central to the lived experience. Meaningful living was woven throughout all the narratives. As Gail shared, “I’ve been very lucky to do a lot of wonderful things in my life. I do a lot of gardening. I do bonsai. We do something every weekend. We traveled to Australia and New Zealand, Machu Picchu is next. I stay busy.”

Even though many of the studies garner evidence-based findings from an empirical and cognitive lens, the essence of the individual's life story as the illness progresses through time is a new frontier. Many women share similar perceptions of the disease but the time frame and methods of coping were different with each participant. Not all meaning found in life is sequential. The purpose of this phenomenological study on the lived experience is to explore a deeper understanding of the lived experience and the connection it may have in building a pathway to understanding the way of transition in the surveillance phase. It is important to understand the experience of breast cancer as it relates to living a liminal life post-acute treatment. Little research has explored the concept of survivorship, especially in regards to the surveillance phase of recovery.

Each theme compliments the other and created a better understanding of grappling with sudden change: transilience, transition with all the intricacies, and lastly, acceptance, which cultivated the true essence of surveillance: liminality. As such, themes are embedded in repetitive or variant, often disparate expressions of social behavior or verbal interaction. This iteration makes themes identifiable and converts them from the emic-implicit meaning of participants to the etic-explicit meaning of the researcher (Ugarizza & De Santis, 2000). The themes of transilience, transition, and acceptance overlapped in many of the narratives shared by the participants. Each of the themes merged as path work to a liminal place and the true essence of surveillance.

Each participant while living in limbo created some type of structure in order to cope with the ongoing complexity of cancer. They all assumed great responsibility for their own health and well-being and showed courage, strength, and an increased desire to help others even on the threshold of surveillance. According to Meleis, being between

two worlds can be likened to finding oneself in between the world of healthy and the world of the ill, a condition marked by alienation. A healthy transition is characterized by connectedness, confidence, subjective well-being, mastery, and successful coping (Melies, 2010).

A study done by Travado and Reis (2013) utilized a cognitive developmental approach that addresses the meanings women with breast cancer attach to their illness within a cognitive-developmental framework. The aim of the study was twofold: (1) to identify the content of women's meanings in five domains of breast cancer representation (identity, causes, consequences, timeline, and controllability), and (2) to verify if those meanings can be classified developmentally and propose a developmental sequence of meanings for breast cancer. Fifty women treated for breast cancer, as outpatients by the Breast Surgery Multidisciplinary Team at Hospital S. José, Lisbon, Portugal, were randomly selected and interviewed using a semi-structured method in order to obtain data on the significance they attached to their illness. A typical breast cancer representation profile was identified: 74% of women know their diagnosis, 70% conceive its causes as external factors, 50% refer to emotional and functional changes as main consequences, 62% are expectant towards the future, and 36% considered themselves cured. It was possible to classify women's illness meanings into different developmental levels: the majority of women acceded only to lower (level 2 = 36%) and intermediate levels (level 3 = 50%). A developmental sequence of meanings for breast cancer was presented (Travado & Reis, 2013).

The participants' acknowledgement of their emotional and physical challenges illuminated a new sense of being and gave roots to making meaning out of their malady.

The way of transition for many of the participants in order to accept the big change in their life related to the diagnosis of cancer spirituality, in this limbo state, was a significant factor enabling them to move forward when not knowing what's next. Each individual may have a unique perspective of making meaning whether it is through holistic alternatives such as the arts, journaling, music, or renewed sense of spirituality, which enhanced meaning and an improved connectedness to life.

Studies have shown that 41% to 94% of patients want their health care provider to be aware of their spiritual requirements during medical treatment (Koenig, 2009). The importance of healing body, mind, and spirit is an essential component in accepting and coping with a chronic illness. Both quantitative and qualitative research reports a strong link between religious and spiritual beliefs and hope, which is an essential concept for those suffering from cancer. In addition, caregivers of the patients suffering from a chronic illness such as breast cancer tend to also rely heavily on spiritual connectedness to cope with the burden (Flannelly et al., 2002). Cancer is still the most feared of all diagnoses. It conjures up negative emotions in the general population. A prominent physician and cancer historian, Dr. Mukherjee, titled his 2010 book *The Emperor of all Maladies*, which is a historical description of how many health care professionals and lay persons still perceive this disease when compared to all other illnesses. He addresses the fear of receiving a cancer diagnosis compared to any other disease, which pale in comparison. A cancer diagnosis stops time for some and creates stress that may manifest differently in each person as they navigate the seas of uncertainty when living with cancer. It is vitally important that research recognizes the importance of how a patient lives within the context of illness (Mukherjee, 2010).

Meaning was found in the memory of the disease situated in time. The emergence of making sense out of tragedy can improve all health outcomes regardless of the illness. Coping and quality of life with the basis of spiritual factors may give the ability to find meaning, accept illness, and inevitably death while accepting mortality (O'Neill, 1998). A strong conscious awareness of time was intertwined with how each participant created meaning from the illness itself as well as how they were more cognizant how time was spent in an ordinary day. Time is seen as an undercurrent through which all their memories originated as a point of reference to change and transition in the trajectory of illness. It is common knowledge that time is central to our understanding of our life stories. Narratives provide a means of studying the evolution of meanings of all experiences from the participant's language. For this study specifically, the meaning of illness over a time line of recovery while living in limbo in the surveillance phase of recovery.

Healing is related to wholeness, and wholeness is experienced in connection with others. Illness can facilitate connection (Egnew, 2005). The lived meaning is the way a person understands his or her world as real and meaningful. Lived meanings describe those aspects of a situation as experienced by the person in it (van Manen, 1990). The resiliency the participants exuded was created by a culmination of all the themes. Moving from the past to the present and looking at the future creating meaning out of each day was crucial to their mental health. Addressing it from an intentionality lens and the phenomenological perspective indicates the connectedness to the world and helps to reflect on experiences and thought (van Manen, 1990). Many of the women with their stories shared the fear of the unknown and living in a type of neutral zone. Many of the



participants shared the need to decrease stress and fear in their life thinking it may contribute to a recurrence of cancer.

A meta-analysis study done by Boals, Banks, Hathaway, and Schuettler (2011) examined cognitive words in narratives of negative experiences and studied the process of meaning making and the relationship it has on closure and coping from a stressful event. The findings suggested cognitive word use, a past predictor of beneficial outcomes from the expressive writing intervention, was related to the process of meaning making. In the first study, the finding was true for memories that lacked psychological closure. The second study replicated the finding that cognitive word use is related to the meaning-making process using an alternative measure of meaning making. This study focused more on examination of the process of meaning without much mention of other physical or emotional components. Reflection and helping others enabled the participants to make meaning out of the breast cancer experience. Many of the participants shared that through journaling, meditation, yoga, and other aesthetic healing measures were essential in the transition and creating a new life. Constructivists give voice to the influence of the larger social structure on shaping the everyday lived experience, but also view human beings at times as active protagonists in the process of their own “becoming” (Carr, 2010). The liminal pathway creates a new way for the participant to experience some sense of creating normality.

Even though there are various pathways to understanding liminality in surveillance, it is a concept that interconnects many theories as it pertains to rites of passage. An essential component of the liminal process for the participants unfolded in the post-liminal phase of acceptance. The phase of acceptance was steeped in returning

to the old self, whether physically, spiritually, or emotionally. However, making meaning was a product of sudden change and reprioritizing life. Meaning making for the participants manifested in enjoyment in reflecting on life, whether it be walking in the bonsai gardens or painting, music, or writing in a journal.

Many researchers describe the notion or concept by explaining the need for holistic healing to define identity development, awareness of self, meaning and purpose, and involve increasing openness to exploring relationships with an intangible and pervasive power or essence that exists beyond human knowing (Estanek, 2006). Many psychologists describe spirituality as a process through which humans seek to discover, hold, and transform what they hold sacred in their lives (Samuel & Kannappan, 2011). Reductionism is the ambition to make reflection and emulate the unreflective life, making it a means to an end (van Manen, 1990). The literature explains aesthetic reflection as a psychological essence, the lived experience and understanding illness is the foundation to coping, quality of life, and many other concepts (Krok, 2008).

A study by van der Spek et al. (2013) was conducted in an effort to gain more insight in the meaning making process. The researchers conducted four focus groups with 23 cancer survivors on this topic. Participants responded to questions about experienced meaning making, perceived changes in meaning making after cancer, and the perceived need for help in this area. The most frequently mentioned attributes were meaning making themes of relationships and shared cancer experiences. Cancer survivors experienced enhanced meaning after cancer through relationships, experiences, resilience, goal-orientation, and leaving a legacy. Time was seen as a trajectory from diagnosis to death. Some participants, however, also said to have also experienced a loss

of meaning in their lives through experiences, social roles, relationships, and uncertainties about the future. The results indicated that there is a group of cancer survivors that has succeeded in meaning making efforts who have experienced sometimes even more meaning in life than before diagnosis, while there is also a considerable group of survivors that struggled with meaning making and has an unmet need for the same. The results of this study contributed in developing a meaning centered intervention for cancer survivors (van der Spek et al., 2013).

The relationship connects to the present study and reveals a positive correlation in enhancing meaning in life and creating well-being in order to adapt to a chronic illness and improve one's quality of life. The women in this study created a conscious effort to accept the changes in their health status and with reflection and courage looked back on the journey to resolve and make meaning out of their everyday lives through sharing their stories. The narratives are an indispensable source for understanding human action as situated in the temporal (Benner, 1994). As Bridges (2001) posits:

[ the way of life is a journey, a journey along a winding path. ” All rising to a great place, all rising to great place wrote Francis Bacon, is by a winding stair.” The mechanistic world is made up of the shortest distances, straight lines on a flat surface but life fishtailed its way across the undulating landscape. If you want to live, you need to give yourself over to the way of transition. To let go when life present you with time of ending, to abandon yourself to the neutral zone when that is where you find yourself, to seize the opportunity to make a new beginning when the moment presents itself (Bridges,2001).

**Comment [JA4]:** Where does this quotation begin/end?

**Comment [JA5]:** This citation is not in the reference list. and it requires a page number.

Several factors contributing to the marginalization of alternative holistic methods and approaches of healing diseases in health care have been identified through research. These factors include the variety of barriers that exist at individual, professional, and organizational levels (Carr, 2010). More research is needed, however, to better understand how these barriers operate and how they are experienced at the bedside as well as in the outpatient setting. This research also reinforces Frankl's (2004) belief that one's approach to everything from life threatening challenges to everyday situations helps to shape the meaning of our lives. The nature of the experience may garner common themes however each individual shapes the experience to make sense within their own life with breast cancer. The reflection upon the illness allowed the participants to verbalize the phenomena of the lived experience of breast cancer in a distinct personal, transitional pathway. The nature of this study separates what may appear to be common knowledge to others; nonetheless, it sheds light on the true essence of the experience on a deeper level. The study of these essences, described only as the person living the situation can, elaborate on the nature or the meaning of something (Merleau-Ponty, 1962).

In each narrative discourse a hermeneutical phenomenological approach allowed the researcher to hear and interpret each person's language as unique. Applying van Manen's (1990) six research activities enabled the researcher to seek meaning and to understand the true essence of being a woman living within this time frame in this particular phase of recovery. Sometimes the women felt a bit alienated after their diagnosis. Early in the illness this related to the realization that others can never really know how they feel as a result of being a "cancer patient." It is important that the women

were acknowledged from an individual lens and their stories were heard. Frankl (2004) refers to the meaning of life as logos, suggesting that soul and hence spirituality with the meaning of life. Meaning was created by the participants through the various sources, such as a social and spiritual connectedness, exercise, meditation, prayer, and creating holistic health alternatives to healing rather than focusing on the illness itself. Some studies, although not able to explicitly explain variables, have resulted in data that suggest that just participating in organized activities is enough to make a difference in health outcomes (Baker, 2003). Healing and acceptance by the participants appeared to be facilitated by letting go of the past, staying positive in the transition phase and the time of limbo, and making meaning out of the chaos by helping others with cancer. Acceptance was part of the liminal pathway to ensure order and purpose was regained even in the place of “betwixt and between” while living in the surveillance phase of recovery.

Kiehl, Carson, and Dykes (2007) conducted a study about acceptance and adaptation that used both quantitative and qualitative methods in determining family adaptation and chronic illness. Quantitative data were gathered using two surveys, and interviews were used to gather qualitative data. Results from each were compared with validate conclusions. A careful examination of these themes indicated that was high level of congruence with regard to identification of adaptive related to chronic illness. Overall, the in-depth study revealed that adaptation is crucial but challenging and complex and sometimes is never addressed by traditional medicine practices. Cumulative stress and fatigue can eventually overwhelm the entire family system to the point of exhaustion and

even despair if these are not effectively managed and balanced with positive life experiences (Kiehl et al., 2007). Understanding the liminal place at this juncture may help to eliminate stressors in a chronic illness. Thus, positive effects can have an effect on transformational health enhancing behaviors while in the liminal place of surveillance. The focus on the experience of healing evoked positive attributes while experiencing one or more of the three themes of transilience, transition, and acceptance.

Many of the participants shared that by helping others in the cancer support group gave them a purpose to live. The language in the narratives in re-telling their story focused on each word or phrase to which the individual engaged in the process or the story of their journey and the forward progression to a new reality. The liminal place of illness and wellness is an ongoing process. Even when there are temporary setbacks in the recovery phase, acceptance and movement forward is always toward wellness.

#### **Liminality: The Essence of Surveillance**

The themes of transilience, transition, and acceptance created a liminal pathway in facing breast cancer for the participants. The surveillance time is the time of being in limbo while in the process of change. All the participants inhabited a liminal space while in the surveillance phase of recovery. It is a place where the person at times is healthy and at other times ill. Although not all cases of liminality are perceived negative, liminal stages are sometimes seen as sacred or representing hope (Jackson, 2005). From a sociocultural perspective, a threshold when an individual has lost one identity and is in the process of reconstructing a new identity that is meaningful to them and to their community is known as liminality (Turner, 1964).

The concept of liminality comes from clinical psychology by way of anthropology. Turner based insights on van Gennep's *The Rights of Passage* (1960). Van Gennep was the pioneer in describing ways in which time and space are altered during a psychosocial transition. He distinguished three phases in the rites of passage: separation, transition, and incorporation, which were fundamental for development of Turner's understanding of ritual process. Turner's great contribution to understanding the relationship between space and transformation is significant in the realm of transitional phases of liminality (Moore, 1991). Liminality denotes the middle state of initiation rules, as mentioned before, the betwixt and between. The condition was premised on initiation in a social context and conducted ritually pertaining to social status. The application of the concept of liminality to the analytical process of change and transformation is obvious. Liminality, therefore, is the very essence of effective analytical work, the goal of which is change and transformation (Moore, 1991).

Surveillance is a liminal place of uncertainty and at times a tumultuous pathway to attain a sense of wholeness again. For the breast cancer survivor, the transition from being healthy and living with cancer can be a transformative time in one's life. Most of the participants in this study were in a period of flux while living with breast cancer. The three themes identified in the liminal pathway in regards to surveillance are: transience, transition, and acceptance. According to Meleis (2010), the transition process starts at diagnosis with the separation, followed by a phase of transition or liminality, and ends with the phase of incorporation. Most of the participant's health goals were to have the best health possible within the realm of cancer. There are a multitude of factors that can make a person adapt better to adversity than others. Each individual theme of

transilience, transition, and acceptance emerged in all the narratives at one point or another and revealed a liminal pathway that enabled resolution and moving forward with this health challenge.

Improving resiliency increases the understanding of the process that individuals use to transform an adverse health situation, build on it, and assist a patient in their progression to wellness, which can be associated with becoming resilient (Polk, 1997). By reflecting upon the timeline of the illness and the present stage of surveillance, each participant had common characteristics mentioned in the prior studies. Similarities such as good or improved health, easy-going temperament, hope, optimism, social support, and spiritual rituals were all seen as positive attributes in the personality while battling their disease.

Breast cancer rates continue to grow, which inversely means there are more survivors. The only difference with breast cancer is that women are both surviving and dying by the thousands each year. It is imperative to continue research in breast cancer in the surveillance phase to reach higher levels of wellness as well as preventing the physical and emotional side-effects related to cancer treatments needs in this ever-growing population. Another study done by Blows, Bird, Seymour, and Cox (2012) was conducted utilizing liminality as a framework for understanding experience of cancer survivorship in general. The study utilized a textual narrative approach and arranged into groups according to the stage of the cancer on which they focused. Ten studies were included for review, which included pre-cancer risk, treatment, and post-treatment studies that included survivors at various points of the cancer trajectory. The researchers



concluded during their analysis that liminality was a relevant means of conceptualizing the cancer experience (Blows et al., 2012).

Studies regarding the connection between transition and recovery from a chronic illness suggest that fluctuating emotions may play an important role in the road to recovery. Breast cancers' uncertain landscape requires navigation through radical change. The need for creative modes of healing and adaptation in this liminal place is imperative in the normal progression to health and well-being. A study done by Molzahn, Bruce, and Shields (2008) explored people with chronic kidney disease (CKD) and their experiences of liminality associated with CKD and its treatment. A qualitative design was used to study the liminal experiences of people with CKD. The study included 100 narratives and 62 men and 38 women. The ages ranged from 21 to 88 years old. Data analysis was situated in a constructive it approaches with narrative inquiry that attended to temporality, social reality, and place. The findings determined that living with dialysis or waiting for transplantation became new and uncertain for many. The themes found were living/not living, independence/dependence while living in the liminal experience, and the in between time. The participants' narratives reflected the liminal experience of restrictions/freedom, not normal/normal, worse/better, alone/connected. A strong theme of support from family members and health professionals was found throughout the stories. Understanding liminality may help support patients who dwell in such in-between spaces. The importance of the study for nurses was acknowledging that liminal spaces opens up understanding to health professionals to the complexities of living with chronic diseases (Molzahn et al., 2008).

Liminality is linked with notions of threshold or betwixt and between where opposites intersect (Turner, 1994). Many of the participants in surveillance seemed to go through phases. The liminal pathway is not a clear pathway into the future while living with an unpredictable disease. The first phase of diagnosis was a sudden change in the participant's life and a disruption of their temporality. The second phase is a transitional and a time of uncertainty and managing the cancer, and lastly was the phase of acceptance, which gradually initiated a path to transformation. The in-between time of transition was an adjusting time that enabled each person to create ways of achieving optimal health. The path of liminality as it pertains to the surveillance phase of recovery in breast cancer is more of a passage to long-term survivorship rather than staying in an ambiguous state between health and illness.

Liminality is derived from "limen," meaning threshold. The concept of the "liminal space" as introduced by Turner (1994), suggests the idea of ambiguity and ambivalence. This in-between space should allow active exchanges of ideologies, concepts, and methods of working. There is an indication of a transition from one state or space to another and an on-going search for answers, yet the end point might not or need not be defined. Therefore, the "liminal space" might be read as a metaphorical realm where ideas and concepts - artistic, political, cultural, social, or otherwise - are in constant states of contestation and negotiation (Le Ann 2006). There is an importance exploring the road of transition by examining the time of diagnosis and the future while living in the meantime of the illness. The peculiar place on the liminal path is neither here, at the entrance, nor there, at the exit, but both.



*Figure 4.* The liminal path of surveillance: The ambiguous entrance and exit of illness (Amado, 2015).

Liminality translates as a deep lived experience in which a person understands himself or herself on the one hand as belonging to the world of the well simultaneously to a “now” and a “then,” and, on the other, as being in the world of the ill in a non-linear and dynamic pathway to healing. The liminal place is a period of time in surveillance where time, space, body, and lived relations create a new reality. It is a winding path that changes from day to day. The liminal experience often implies the segregation of the breast cancer patient to another physical space where they are on their own, floating at times between certainty and uncertainty. They must move on, and in the moment embrace their new reality and life as a survivor. It is a time of change, when a person who is diagnosed with cancer cannot see a clear path of where they are going or what is next.

As a result, the participants strive to find ways to gain a sense of control in the quest for calm and stability in this turbulent time of the unknown while living with breast

cancer. Most of the participants, even though initially shocked by the realization of the diagnosis itself, were left cautiously hopeful for a better future. Disease that has transfigured them forever has created a road to recovery. Even though the liminal experience of breast cancer created a shift in their quality of life, each participant, while on the path of uncertainty, learned the things they valued the most in life. Many of the participants realized there was a long road ahead of them.

A liminal pathway can be felt in the Beatles song "The Long and Winding Road:"

The long and winding road that leads to your door

Will never disappear I've seen that road before

It always leads me here lead me to your door

The wild and windy night that the rain washed away

Has left a pool of tears crying for the day

Why leave me standing here

Let me know the way many times I've been alone and many times I've cried

Any way you'll never know

The many ways I've tried but still they lead me back

To the long winding road

You left me standing here a long long time ago

Don't leave me waiting here

Lead me to your door but still they lead me back

To the long winding road you left me standing here

A long long time ago don't keep me waiting here

Lead me to your door (Lennon & McCartney, 1970).

Since there has been little research exploring liminality in breast cancer, there are even fewer exploring the lived experiences of breast cancer survivors while in the surveillance phase of recovery. There are many questions that may require further research. For instance, it would be interesting to explore whether the experiences of liminality differ in women with the various treatment that they received during their breast cancer journey. It may be interesting also to explore liminal places such as the participant's views on death and dying in order to provide better care on the liminal pathway in surveillance.

The participants in this specific study reflected upon their life experience living with a cancer diagnosis and through a conscious effort to create balance out of chaos and managing to enhance their physical, emotional, and spiritual health. The emergence of liminal pathways to understand survivorship is essential to accumulate further insight into positive transitioning. The need to examine liminality is of utmost importance in order to understand transformation in all stages of the breast cancer trajectory.

### **Implications for Nursing Education**

Implications of this study for nursing education are significant for a various important reasons. It is vital for nurse educators to teach students about the long-term physical, emotional, and spiritual effects of breast cancer. To integrate holistic health alternatives into a curriculum would be an excellent method to introduce cultural competency to the student. In this study, the lived experience of survivorship increased knowledge of the disease and an understanding of differences in recovery for each patient through exploring the essence of the disease from the patient's perspective. It is

important to incorporate innovative methods of teaching to reduce any fears the student has with obtaining a patient's life history and not just the illness history. Nurses can support those who are suffering by assisting them to identify their patient's needs and to design specific interventions to maintain well-being.

Another factor this study revealed is the importance of understanding the concept of liminality in nursing science, which will allow nurses to be more sensitized in treating each patient holistically. Research about post-treatment in the breast cancer patient will allow for nursing education to garner important knowledge about the cancer care continuum from initial diagnosis, treatment, and the remainder of life. These findings will add to the body of nursing knowledge and help to develop educational programs and will prepare novice as well as expert nurses to better serve this growing population. This study provides an alternative method for health care professionals to create individual navigation plans of care for the cancer patient premised on the individual's perspective as they traverse the liminal pathway of breast cancer. The idea of a cancer survivorship care plan can be integrated in the core curriculum and enable students to better care for this special population. This component of cancer care could be incorporated into the community health module and allow for improved learning outcomes related to breast cancer needs in the community.

### **Implications for Nursing Practice**

This study highlighted the need for understanding the transition and facing illness. Nurses have an important role regarding medical advice and can have a direct impact on how the patient understands the disease process. Increased knowledge in the clinical arena may allow for a customized plan of care for each woman who is facing a life with

breast cancer. The improvements for treating a survivor increases awareness of the individual's needs, provides important information for the practitioner's knowledge about the health challenges that a survivor faces, and reduces unwarranted fears of the disease. When the patient is under surveillance, the in-between time may not warrant an oncologist appointment for every health issue. A better informed nursing community, such as an oncology nurse at an outpatient clinic or a family nurse practitioner in the community setting, may be better equipped to address latent effects that may otherwise not be recognized. Therefore, in nursing practice, incorporating holistic approaches in the history and physical assessments of this population is an essential part for their ongoing plan of care. This study enhances the knowledge base of nurses and advanced practice nurses to provide thorough, holistic care for those women who are sometimes unable to navigate the complex health care system. Oncology nurses need to be aware of the sudden transition in the life of women so they can provide more effective and holistic care during this difficult time. The time frame is the time after treatment ends and the maintenance period with medications and follow-up appointments begins. Nurses need to be aware of a multitude of factors, including motivational reasons influencing coping mechanisms of patients newly diagnosed with breast cancer. Lastly, they need to recognize that care does not end at the completion of active treatment but will continue for years to come, even when treatment is over.

### **Implications for Nursing Research**

The findings from this research study contributed to the existing gap of nursing knowledge regarding the phenomenon of women living with breast cancer in the surveillance phase of recovery. This study explored the overall well - being of the breast

cancer patient from a narrative perspective from their time of diagnosis to post-surgery and treatment. Nursing research in this arena will add valuable knowledge to existing findings related to the topic. A greater emphasis on the continuum of care post-treatment could allow for further exploration of this growing phenomenon. The current study suggests a strong connection between ways of transition and exploring a liminal pathway to long-term survivorship. Further studies might examine similarities and differences in the liminal pathway pertaining to treatments while in this phase of recovery. Most importantly, findings in this study may create new interventions that could improve delivery of care and facilitate a smoother transition in the recovery stage of the disease process. Continued research in this area gains importance as the numbers of survivors increase.

Hopefully this research will improve the way health care providers disseminate education on survivorship care. Moreover, further research on the concept of survivorship within this specific time frame adds to the body of nursing knowledge on this specific research topic. Further research as a concept analysis of liminality may allow exploration and development associated with liminal pathways in chronic illness and facilitates translation of the concept across all disciplines.

### **Implications for Health/Public Policy**

In review of this study conducted on breast cancer, prevention costs are greatly reduced when the disease is caught early. In the public health arena, if screening and treatment are done early mortality rates decrease. Overall health costs in survivorship could be addressed earlier at initial diagnosis and the time of individual treatment plans with the exploration of the needs while on a liminal path of recovery. However, in the



overall treatment plan in the surveillance phase of recovery can last a lifetime for some women. Several national action plans about survivorship exist in the public policy domain. The National Cancer Institute (NCI) and the Centers for Disease Control and Prevention (CDC) have made efforts to amass information that will improve quality of life for all survivors. With understanding surveillance, there can be significant savings in overall health care costs that may last the remainder of life. Battling this disease is not over when treatment stops. Each year after treatment, there can be latent effects that warrant interventions. However, these effects may not be covered under the cancer care component of a policy. With a sound program to monitor survivors, the problems may be addressed early to ward off greater care costs. This awareness enhances public policy in health care because it would address secondary cancers, promote a stronger management of the disease, minimize potential distress that accompanies cancer, and provide community-based cancer survivorship clinics (Odle, 2011).

From a nursing perspective, the topic of breast cancer survivorship in the surveillance phase is important to study in all the above mentioned areas of education, practice, research, and policy. The need to investigate this specific phenomenon may further advance the practice of nursing. More research is needed into the liminal experiences with chronic illnesses such as breast cancer and how understanding the liminal pathway during surveillance can improve the overall quality of life.

#### **Strengths/Limitations of the Study**

This study embraced its strengths and concurrently the limitations. The purpose of this study was to explore the lived experiences of women living with breast cancer in a surveillance stage of recovering and living with breast cancer. This study provided

insight into the participants' lived experiences of the way women adapt by the use of narrative discourse from their personal journey through illness. The findings of this research study are limited by the possible homogeneous demographic characteristics of the research participants such as the locale of the study. A different socioeconomic area may warrant different results. Another limitation may be the age of the participants, who were mainly between 40-75 years of age with the exception of one who was diagnosed at the age of 29, which may mitigate different liminal pathways pertaining to coping in the surveillance phase of recovery. The need to explore younger survivors could be a premise for further research on this topic.

#### **Recommendations for Future Research**

Research studies conducted on this specific population in relation to the surveillance phase of breast cancer are limited from a narrative phenomenological approach, thus providing many opportunities for further studies on a variety of topics. Future studies could improve upon the delivery of care for someone struggling with chronic disease. Research studies focused to foster caring environments that encourage the discovery of liminality may help make sense of the lived experiences of wellness within an illness for breast cancer survivors. During this time of uncertainty between cure and recurrence, developing a liminal pathway is vital for developing meaningful support systems in breast cancer and enhances delivery of care for this patient population.

Innovative studies such as blending phenomenology and writing of illness narratives from the patient perspective (phenomenography) would allow great insight into the lived experience within the context of one's illness and promote alternative ways in gaining insight and understanding chronic illnesses. Gaining a deeper understanding

from the women's illness narratives is a progressive and creative method in exploring their lived experience in creating a liminal pathway to survivorship. This study may stimulate thought provoking dialogue in nursing circles about innovative paths about illness, health, and healing throughout the trajectory of living with breast cancer.

### **Summary and Conclusion**

Chapter Five discussed the findings of the phenomenological inquiry into the lived experience of women with breast cancer who are post-surgery and treatment and are in a surveillance phase of the disease. This study utilized a hermeneutic phenomenological approach to explore the narratives and life stories of this specific population. Thirteen participants shared their stories, allowing the researcher to understand their experiences through their stories, thereby accomplishing the goals of the study. Through open and unrestrained dialogue, focused listening, and reading and re-writing of the texts by the researcher, themes emerged. The phenomenon was explored in-depth and contributed to a gap in the body of knowledge for nursing research.

The themes that arose from the study were transilience, transition, and acceptance. With the emergence of the above themes, the true essence of surveillance was concept of liminality. Research that applies understanding liminality in regards to breast cancer and the surveillance phase of recovery may facilitate understanding this phenomenon. Exploring the liminal pathway may help with the assertion that the liminal state experienced by breast cancer survivors may or may not be permanent. The findings of this study align itself with current research on qualitative research understanding liminality as a framework for exploring the lived experiences of cancer survivorship. These themes create a narrative path in finding a resolution to a health challenge and the

ability to move forward. The very essence of the cancer journey lies in understanding the liminal pathway to healing. Understanding the implications of liminality creates a shift in psychological, physiological, emotional, and spiritual consequences. This study may provide an innovative method for further research in reducing, relieving, and understanding the uncertainties associated with the surveillance phase of recovery by examining the narratives of health and illness as it unfolds in lived time.

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## APPENDIX A

## IRB APPROVAL LETTER



OFFICE OF THE PROVOST

11300 NE Second Avenue  
 Miami Shores, FL 33161-6695  
 phone 305-899-3020  
 800-796-6000, ext. 3020  
 fax 305-899-3026  
 www.barry.edu

Research with Human Subjects  
 Protocol Review

Date: December 6, 2013

Protocol Number: 131127  
 Title: The Lived Experience of Women with Breast Cancer During the Surveillance Phase of Recovery: A Hermeneutic Phenomenological Inquiry

Meeting Date: November 20, 2013

Researcher Name: Ms. Patricia Amado  
 Address: 8512 Tourmaline Blvd.  
 Boynton Beach, FL 33472

Sponsor: Dr. Mary Colvin  
 College of Health Science, Div. of Nursing

Dear Ms. Amado:

On behalf of the Barry University Institutional Review Board (IRB), I have verified that the specific changes requested by the convened IRB on November 20 2013 have been made.

It is the IRB's judgment that the rights and welfare of the individuals who may be asked to participate in this study will be respected; that the proposed research, including the process of obtaining informed consent, will be conducted in a manner consistent with requirements and that the potential benefits to participants and to others warrant the risks participants may choose to incur. You may, therefore, proceed with data collection.

As principal investigator of this protocol, it is your responsibility to make sure that this study is conducted as approved by the IRB. Any modifications to the protocol or consent form, initiated by you or by the sponsor, will require prior approval, which you may request by completing a protocol modification form.

It is a condition of this approval that you report promptly to the IRB any serious, unanticipated adverse events experienced by participants in the course of this research, whether or not they are directly related to the study protocol. These adverse events

include, but may not be limited to, any experience that is fatal or immediately life-threatening, is permanently disabling, requires (or prolongs) inpatient hospitalization, or is a congenital anomaly cancer or overdose.

The approval granted expires on November 30, 2014. Should you wish to maintain this protocol in an active status beyond that date, you will need to provide the IRB with and IRB Application for Continuing Review (Progress Report) summarizing study results to date. The IRB will request a progress report from you approximately three months before the anniversary date of your current approval.

If you have questions about these procedures, or need any additional assistance from the IRB, please call the IRB point of contact, Mrs. Barbara Cook at (305)899-3020 or send an e-mail to [LBachelor@mail.barry.edu](mailto:LBachelor@mail.barry.edu). Finally, please review your professional liability insurance to make sure your coverage includes the activities in this study.

Sincerely,



Linda Bacheller, Psy.D., J.D.  
Chair, Institutional Review Board  
Barry University  
Box Psychology  
11300 NE 2nd Avenue  
Miami Shores, FL 33161

Cc: Dr. Mary Colvin

Note: The investigator will be solely responsible and strictly accountable for any deviation from or failure to follow the research protocol as approved and will hold Barry University harmless from all claims against it arising from said deviation or failure.

**APPENDIX B**

**BARRY UNIVERSITY INFORMED CONSENT**



11300 NE Second Avenue  
Miami Shores, FL 33161-6695  
phone 305-899-3020  
800-756-6000, ext. 3020  
fax 305-899-3026  
www.barry.edu

OFFICE OF THE PROVOST  
INSTITUTIONAL REVIEW BOARD Research with Human Subjects  
Protocol Review

To: Ms. Patricia Amado  
8512 Tourmaline Blvd.  
Boynton Beach, FL 33472

From: Linda Bacheller Linda Bacheller, Psy.D., J.D.  
Chair, Institutional Review Board

Date: October 1, 2014

Protocol Number: 131127  
Protocol Title: The Lived Experience of Women with Breast Cancer  
During the Surveillance Phase of Recovery: A  
Hermeneutic Phenomenological Inquiry

Dear Ms. Amado:

Thank you for sending the request for modifications indicating that you would like to make changes to your protocol regarding:

- 1. Date extension of study from November 30, 2014 to November 29, 2015.

The above changes are accepted. You may proceed with your collection of data. The approval granted expires on November 29, 2015.

Sincerely,

Linda Bacheller, Psy.D., J.D.  
Chair, Institutional Review Board  
Barry University  
Box Psychology  
11300 NE 2nd Avenue  
Miami Shores, FL 33161

If you have any questions, please contact Barbara Cook at: 305-899-3020

\*\*\*\*\*

Note: The investigator will be solely responsible and strictly accountable for any deviation from or failure to follow the research protocol as approved and will hold Barry University harmless from all claims against it arising from said deviation or failure.

Approved by Barry University IRB :

Date : 12/6/13

Signature : *Amado Amado, PhD, JD*

Institutional Review Board  
Protocol Form  
February, 00 8

APPENDIX B

BARRY UNIVERSITY INFORMED CONSENT

Your participation in a research project is requested. The title of the study is: The Lived Experience of Women with Breast Cancer in the Surveillance Phase of Recovery: A Hermeneutic Phenomenological Inquiry. The research is being conducted by Patricia Kathryn Amado, a student in the College of Health Sciences, Division of Nursing and is seeking information that will be useful in the field of Nursing Practice and Research. The aims of the research are to explore the lived experience of breast cancer survivors and to give voice to post treatment survivors to articulate their individual experiences. This study will seek to provide a description of breast cancer survivorship post treatment to gain understanding of the essence of the phenomenon. In accordance with these aims, the following procedures will be used: semi-structured, face-to-face audiotaped interviews. The interview will take place in an informal, private room in a survivorship clinic. The interviews will last approximately one hour. The number of participants is anticipated to be approximately 15-20.

If you decide to participate in this research, you will be to do the following: a) sign an informed consent and b) participate in a one-hour interview that will be audio recorded c) choose a pseudonym for the study prior to filling out demographic. Your consent to be a research participant is strictly voluntary and should you decline to participate or should you choose to drop out at any time during the study, there will be no adverse effects on the information obtained through the initial interview. The risks of involvement in this study are minimal. There will be no known benefits for participating in this study; however, your participation in this study may help with understanding breast cancer survivorship in the surveillance phase and the experience of living with a chronic illness.

As a research participant, information you provide will be held in confidence to the extent permitted by law. Any published results of the research will refer to group only and no names will be used in the study. Data will be kept in a locked password sensitive file in the researcher's office. Audio tapes will be destroyed post transcription and data will be kept for five years after completion of end of study. Your signed consent form will be kept separate from the data in a locked file cabinet in the researcher's home office.

If you have any questions or concerns regarding the study or your participation in the study, you may contact me, Patricia K. Amado at (561) 573-2152, my chair Dr. Mary Colvin at (305) 899-3039, or the Institutional Review Board point of contact, Barbara Cook, at (305) 899-3020. If you are satisfied with the information provided and are willing to participate in this research, please signify your consent by signing this consent form.

**Voluntary Consent**

I acknowledge that I have been informed of the nature and purposes of this experiment by Patricia K. Amado and that I have read and understand the information presented above, and that I have received a copy of this form for my records. I give my voluntary consent to participate in this experiment.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date



Approved by Barry University IRB :

Date: OCT 15 2014

Signature: *Alb. V. Armstrong, Jr. DPM*

Institutional Review Board  
Protocol Form  
February, 00 1

## APPENDIX B

### BARRY UNIVERSITY INFORMED CONSENT

Your participation in a research project is requested. The title of the study is: The Lived Experience of Women with Breast Cancer in the Surveillance Phase of Recovery: A Hermeneutic Phenomenological Inquiry. The research is being conducted by Patricia Kathryn Amado, a student in the College of Health Sciences, Division of Nursing and is seeking information that will be useful in the field of Nursing Practice and Research. The aims of the research are to explore the lived experience of breast cancer survivors and to give voice to post treatment survivors to articulate their individual experiences. This study will seek to provide a description of breast cancer survivorship post treatment to gain understanding of the essence of the phenomenon. In accordance with these aims, the following procedures will be used: semi-structured, face-to-face audiotaped interviews. The interviews will be at a place mutually decided upon by the researcher and participant. The interviews will last approximately one hour. The number of participants is anticipated to be approximately 15-20.

If you decide to participate in this research, you will be to do the following: a) sign an informed consent and b) participate in a one-hour interview that will be audio recorded c) choose a pseudonym for the study prior to filling out demographic. Your consent to be a research participant is strictly voluntary and should you decline to participate or should you choose to drop out at any time during the study, there will be no adverse effects on the information obtained through the initial interview. The risks of involvement in this study are minimal. There will be no known benefits for participating in this study; however, your participation in this study may help with understanding breast cancer survivorship in the surveillance phase and the experience of living with a chronic illness.

As a research participant, information you provide will be held in confidence to the extent permitted by law. Any published results of the research will refer to group only and no names will be used in the study. Data will be kept in a locked password sensitive file in the researcher's office. Audio tapes will be destroyed post transcription and data will be kept for five years after completion of end of study. Your signed consent form will be kept separate from the data in a locked file cabinet in the researcher's home office.

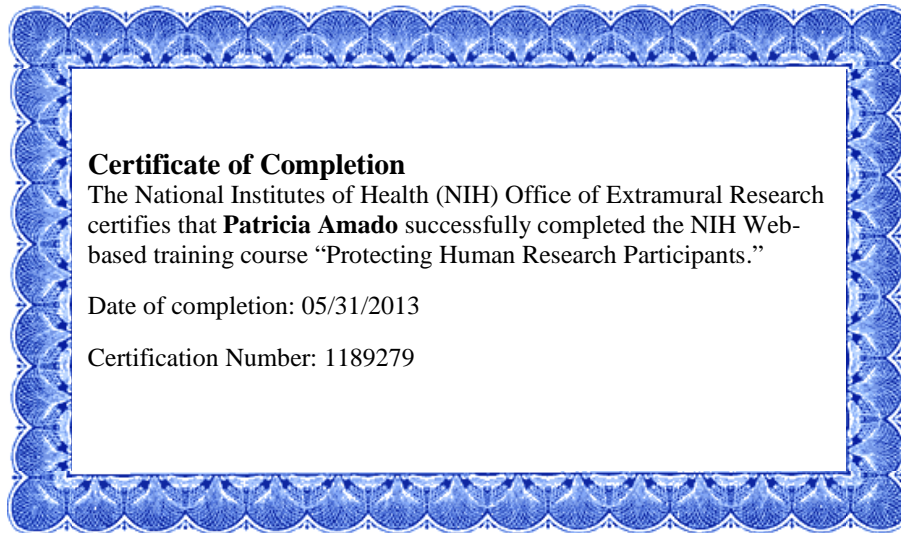
If you have any questions or concerns regarding the study or your participation in the study, you may contact me, Patricia K. Amado at (561) 573-2152, my chair Dr. Mary Colvin at (305) 899-3039, or the Institutional Review Board point of contact, Barbara Cook, at (305) 899-3020. If you are satisfied with the information provided and are willing to participate in this research, please signify your consent by signing this consent form.

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I acknowledge that I have been informed of the nature and purposes of this experiment by Patricia K. Amado and that I have read and understand the information presented above, and that I have received a copy of this form for my records. I give my voluntary consent to participate in

\_\_\_\_\_  
*Signature of Participant*

\_\_\_\_\_  
*Date*



**Certificate of Completion**

The National Institutes of Health (NIH) Office of Extramural Research certifies that **Patricia Amado** successfully completed the NIH Web-based training course "Protecting Human Research Participants."

Date of completion: 05/31/2013

Certification Number: 1189279

**APPENDIX C****LETTER TO ACCESS**

SUBJECT: A Qualitative Research Study of Women with Breast Cancer in the  
Surveillance Phase of Recovery

Hello,

I am a doctoral nursing student at Barry University. I am conducting a study on the lived experience of the breast cancer patient who have completed acute treatment for breast cancer and who have completed the initial treatment regime of surgery, chemotherapy and / or radiation. I plan to collect data from the participants using audio-taped interviews lasting approximately one hour at a mutually agreed upon place by the researcher and participant. I anticipate approximately 10-15 women for this study to briefly discuss my research study. There will be no link to your organization and the study, as the sole purpose of your involvement will be to assist me to recruit women who are willing to share their journey as a breast cancer survivor during the healing period post treatment.

If you have any questions you can call me on my cell phone [REDACTED]

Thank you for your consideration and assistance,

Patricia Kathryn Amado RN, MS, CNS

## APPENDIX D

### THE LIVED EXPERIENCE OF WOMEN WITH BREAST CANCER DURING THE SURVEILLANCE PHASE OF RECOVERY



Would you be willing to participate in a study about understanding survivorship in the surveillance phase of recovery in breast cancer?



YOU CAN PARTICIPATE IF YOU:

1. are a woman between the ages of 25-75
2. speak English
3. are able to share your experience during a one hour audiotaped face-to-face interview.
4. are under surveillance by an oncologist and are receiving regular scheduled check-ups.
5. have undergone surgery, chemotherapy, and/or radiation therapy.

**Thank you for your time and consideration.**

**Patricia K. Amado, RN, MS, CNS Principal Investigator (a doctoral student from Barry University, Florida)**

██████████ or [patricia.amado1@mymail.barry.edu](mailto:patricia.amado1@mymail.barry.edu)

*Barry University Faculty Supervisor: Dr. Mary Colvin*

*Phone: ██████████ Email: mcolvin@barry.edu*

*Barry University IRB Contact: Barbara Cook*

*Phone: (██████████) Email: bcook@barry.edu*

**APPENDIX E**

**LETTERS OF COLLABORATION AND COUSELING**



October 24, 2013

To whom it may concern,

We have free counseling services here at the Survivorship clinic provided by Cindy Collins PhD in health psychology, RD, LD/N. In addition, counseling is also provided by Judy Armstrong ARNP, MSN, BC, OCN and Nancy Thurston LCSW.

If you have any questions, please feel free to contact me at [REDACTED]

Warmest regards,

Judy Armstrong ARNP, MSN, BC, OCN



To whom it may concern,

We are excited to have Patricia Amado commence her study here at our Cancer Survivor clinic. We understand the inclusion and exclusion criteria. We are willing to give her any resources she may need for this project. We understand the purpose of the study and how it will advance nursing practice.



Warmest Regards,

Judy Armstrong ARNP, MSN, BC, OCN

Director of the Survivorship clinic

**APPENDIX F****INTERVIEW QUESTIONS**

1. What was your experience after your diagnosis of breast cancer after initial treatment ended and the surveillance phase of recovery began?
2. Are you familiar with the term surveillance?
3. How did the experience affect you?
4. How did it affect others in your life?
5. Do you attend or have you ever attended support groups?
6. How does facing a chronic illness affect the way you see life now?
7. Do you think about death and dying?
8. Where do you find comfort and solace in dealing with the unknown regarding cancer?

**APPENDIX G****DEMOGRAPHIC QUESTIONNAIRE**

Please answer the following as completely as possible. Please circle which answer applies. If any answer does not exactly fit your experience, feel free to add information that is necessary to answer the question.

Thank you for participating in my study.

Name:

Date: \_/ \_/ \_

Interviewee (pseudonym): \_\_\_\_\_

1. Age range:

a. 25-34

b. 35-44

c. 45-54

d. 55-64

e. 65-75

2. Marital Status:

a. Single

b. Married

c. Divorced/separated

d. Widowed

e. Domestic Partner

3. Number of children: \_\_\_\_\_



## 4. Educational level:

- a. Less than high school
- b. High school
- c. Some college
- d. Undergraduate college degree
- e. Graduate degree (Master's, PhD, EdD, etc.)

## 5. Religion \_\_\_\_\_

## 6. Employment status

- a. Work full time outside of home
- b. Work from home
- c. Work part - time
- d. Unemployed
- e. Stay at home mother

## f. Retired

## 7. Insurance coverage

- a. Full coverage
- b. Partial coverage
- c. No coverage
- d. Medicare/Medicaid

## 8. Stage of cancer upon diagnosis:

- a. Stage I
- b. Stage II
- c. Stage III

## d. Stage IV

9. Age of initial diagnosis\_\_\_\_ (fill in the blank)

10. Treatment and/or surgery: (circle all that apply)

a. surgery type: lumpectomy or mastectomy

b. chemotherapy

c. radiation

11. Length of time to complete treatment \_\_\_\_\_ (fill in the blanks)

12. Length of time from diagnosis to post treatment phase of breast cancer regime \_\_\_\_\_

13. Are you still continuing with regular check- ups with the oncologist? \_\_\_\_\_

## **APPENDIX H**

### **INTERVIEW PROTOCOL**

1. Introduce researcher to the participant.
2. Explain the purpose of the study, the types of questions to be asked, the expected time frame for the interview, the ability to stop the interview and/or withdraw from the study at any point in time, the process of audiotaping and transcribing the interview, and the methods being used to maintain confidentiality.
3. Ask participant if he/she has any questions and give informed consent form to be signed by participant.
4. Ask the participant (s) to choose a pseudo nym to be used as an identifier.
6. Distribute the demographic questionnaire to fill out.
7. Conduct the interview using the guiding questions for the individual interview.
8. Thank the participant(s) at the end of the interview.
9. For the individual interview, inform the participant that the researcher will be contacting them by phone or email within one week to schedule the time for member checking.
10. Take several minutes to self-reflect, take field notes, and journal thoughts and feelings.
11. Transcribe the interview.
12. Analyze the data; write memos to place on story board and journal.

**APPENDIX I**

**FIELD NOTE REFLECTION**

Date: \_\_\_\_\_ Pseudonym: \_\_\_\_\_

Setting of environment:

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Researcher's impressions and thoughts \_\_\_\_\_

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Describe any problems:

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Emotional responses:

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Observations:

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**VITA**

Patricia Kathryn Amado, RN, MS, CNS

March 17, 1961	Born, Union City, PA
1994	BSN, Desales University Center Valley, PA.
2005	MS, Florida Atlantic University Boca Raton, FL
1994-1997	Telemetry RN, Sacred Heart Allentown, PA
1998-2002	Clinical Manager Tenet West Boca Medical Center Boca Raton, FL
2000-2003	Adjunct Faculty Palm Beach State Lake Worth, FL
2003-2008	Adjunct Faculty Florida Atlantic University Boca Raton, FL
2008-2012	Assistant Professor Palm Beach Atlantic University

2011-2014	West Palm Beach, FL Doctoral Student Barry University Miami Shores, FL
2013-Present	Part-Time Lecturer University of Miami Coral Gables, FL

