“AND THEN WHAT HAPPENED?”: THE LIVED EXPERIENCES OF BREAST CANCER SURVIVORS AND THEIR STORIES OF CHANGE AND MEANING

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“AND THEN WHAT HAPPENED?”: THE LIVED EXPERIENCES OF BREAST CANCER SURVIVORS AND THEIR STORIES OF CHANGE AND MEANING

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ABSTRACT

The purpose of this research was to understand the lived experience of breast cancer survivors. The aims were to find out how survivors changed as a result of their illness and what meaning they made of their experience. The questions “so what?” and “then what happened?” were the underlying foci of understanding how it was for the participants to live their daily lives, if changes were positive or negative, and what that meant to the survivors.

The research methodology was qualitative in nature. Philosophically phenomenological in approach, eight breast cancer survivors participated in two separate interviews to provide the case studies for narrative analysis.

Two meta narratives emerged from the interview data: change and meaning. As part of the change meta narrative, there were three major themes. These major themes were negative change, chronic illness, and posttraumatic growth. The negative change theme further divided into four subthemes of invisible illness, invisible God, lost voices, and lost expectations. There were additionally five subthemes under posttraumatic growth: new self perception, new possibilities, new relations with others, new priorities, and new faith. The second meta narrative of meaning had the major theme of mortality.

Survivors reported stories of positive and negative change complete with doubts and fears, as well as renewed relationships and altered priorities. There were reports of anger directed towards God and other people, and there were stories of deeper faith and
altruistic giving to others. As they grappled with understanding their breast cancer, they had to face fears of recurrence and the very real possibility of their own death.

When the active treatment for breast cancer ended, survivors reported struggles with resuming a new life, with a new identity, and new challenges. With the increasing numbers of breast cancer survivors, it is imperative that there is research directed towards the needs of the survivors. The stories shared in the current research can inform counseling practice for provision of the support, advocacy, and mental health care that survivors need to negotiate their survivorship trajectory.
DEDICATION

This dissertation is dedicated to the memory of my parents, James L. and May K. Sadler, Jr. You taught me to work hard, to learn much, to dream big, and to care deeply about others. Both of you had long battles with your own chronic illnesses. You showed me how to live with grace in difficult circumstances, and ultimately, you demonstrated for me how to die with courage and dignity.

It is also dedicated to the memory of my dear friend, Margo Foley, who died all too soon of breast cancer.

I miss you all.
ACKNOWLEDGEMENTS

This is not the dissertation I ever expected to write. When I was diagnosed with breast cancer just after completing my doctoral comprehensive exams, I found that I had no passion for a dissertation about eating disorders. Instead, I did what all graduate faculty warn against—I changed my topic. I became fascinated with hearing other women’s stories about breast cancer. I wanted to know about their experiences during treatment and recovery and about what changed in their lives as a result.

To the women who gave me an intimate look into their lives as impacted by breast cancer, saying “thank you” is simply not adequate. You entrusted me with your stories, and you shared your struggles, fears, doubts, and most of all your hopes. You are the brave ones. You shared your voices with me “at the wall,” and I feel humbled and privileged to have joined you in this sacred space. You have blessed me beyond measure.

To my dissertation chair and advisor, Dr. Cynthia Reynolds, thank you for being a mentor, for allowing me to have the space I needed to negotiate my journey, while supporting me all the way. You have been a true role model for me of a professional counselor and a counselor educator. To Dr. Sharon Kruse, thank you for the “lifetime guarantee” of your guidance to those of us in your Qualitative Research class. I really caught the vision and excitement of qualitative methods in that class. And to the other members of my committee, Dr. Sandra Perosa and Dr. Patricia Parr of The University of Akron, and Dr. Paula Britton, my doctoral internship supervisor from John Carroll University, thank you for giving freely of your time and scholarly expertise.
A special thank you goes to my colleague and friend, Norma Wolfe Bryant, who read all the transcripts and discussed the themes of the data with me. She provided member checking for me and helped me process some of my counter transference with participants.

To our children, Kirsten and Russ Marchand, and Benjamin and Sabine Gerhardt, I appreciate your support and belief. Thank you for countless suggestions about editing and computer techniques, and for the provision of meals and encouragement. I am proud of both of you, the adults you have become, and the partners you chose. And to our two precious granddaughters, Alexandra and Amelia, you give me joy and hope for the future. I pray that you will never experience this dread disease.

To my brother, Jonathan, thank you for being there during my breast cancer and Mother’s illness, and for believing in me always.

To my best friend for life, my husband, Jon, thank you for your belief in me, even when I lost hope. You not only encouraged me during graduate school, but you lovingly walked with me through the valley of breast cancer. Although I was the one diagnosed, I know this disease hurt every part of you also, and yet you always had that extra energy and hope to lift me up. I would not have made it without you. I look forward to the rest of our journey!

Finally! I dedicate this work to you all.
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CHAPTER I
THE PROBLEM

Introduction

“We tell ourselves stories in order to live.” Joan Didion

Breast cancer. Two words that evoke fear, shock, and disbelief in the hearts of most women. There is good reason for the fear. Over 200,000 women were diagnosed with breast cancer in the United States in 2003 (Ganz, et al., 2004), and 213,000 new cases are expected in 2006 (American Cancer Society, 2006). According to the American Cancer Society’s (ACS) Cancer Facts and Figures, 2006, breast cancer is the most common cancer diagnosis in women, with one in eight women in the US affected, totaling approximately 1.2 million (American Cancer Society, 2006; Baum & Andersen, 2001; Keitel & Kopala, 2000). Globally an estimated one million new cases are diagnosed every year (McPherson, Steel, & Dixon, 2000). Over 41,000 women are likely to die from this disease in 2006, making it the second most common cancer death for women after lung cancer (ACS, 2006; Haber, 1995). Cancer, a huge public health problem and the major cause of “premature mortality” (Baum & Andersen, 2001, p. 3; Jemal, et al., 2003), accounts for one in four deaths in the United States, out ranked only by heart disease.
Researchers have been interested in the medical and the psychosocial factors of breast cancer since the late 1940s and 1950s, with the growth of the American Cancer Society (ACS) and the National Cancer Institute (NCI) (Patterson, 1987). While much medical research has addressed etiology, prevention, and treatment measures, the psychosocial research has primarily focused on the early phases of diagnosis, surgery, and initial treatment. It is only recently that research has considered the survivorship trajectory and the longer term aspects of living with breast cancer as a chronic illness (Carter, 1993; Tomich & Helgeson, 2002). Schnipper (2003) posits that the real crisis for the woman begins after the adjuvant treatment of chemotherapy and/or radiation is completed and that the diagnosis and treatment are the “easy part” (p. 14). With mortality rates decreasing since 1990, survivors numbered approximately 2.3 million women in 2002, the most current year for NCI statistics (ACS, 2006); therefore a significant number of women are living today with a breast cancer diagnosis.

What happens to one’s life after such a traumatic event? How is it to be at the mercy of a medical team that prescribes such life-altering treatment, while seemingly without one’s own voice? After the crisis of such a diagnosis, and the invasive nature of treatment modalities, how does the woman view her new life? Some would speculate that change is inevitable, and that survivorship becomes an adaptive process that leads to a new sense of what is normal (Carter, 1993; Charmaz, 1999a, 1999b; Turner, 2003). Many women report restructured life goals and altered priorities, an existential view of their own mortality, renewed relationships, and a deepening spirituality as a result of their cancer experience (Janoff-Bulman, 1999; Taylor, 1983). Some describe a type of epiphany or a major quantum change (Carter, 1989; Jarvis, 1996; Schnipper, 2003).
Much of the research about the medical and psychosocial aspects of breast cancer has been quantitative in nature (Ganz, et al., 2004; McKenna, Zevon, Corn, & Rounds, 1999; Rothrock, Matthews, Sellergren, Fleming & List, 2004; Tomich & Helgeson, 2002). Carter (1993, 1989) and Oktay and Walter (1991) were a few of the early investigators using a qualitative approach that considered the lived experiences of women affected by breast cancer. It was my intent to further their investigations by exploring with breast cancer survivors what their lived experience has been with regard to changes occurring in their lives. The present study was concerned with women who have experienced a breast cancer diagnosis and how they have changed through or been changed by their illness. The specific aim was to hear their stories about their lives after breast cancer, in the new normal state (Charmaz, 1999a, 1999b), living “as if” they are cancer free in the shadow of the reality that recurrence is always possible and with the certainty that change is life’s only constant (Nielsen, 2001; Schnipper, 2003).

Background to the Study

The current research considered the construct of change in the lives of breast cancer survivors. The following sections introduce the concepts of quantum change and chaos theory, breast cancer, and breast cancer survivorship as foundational to the study.

Quantum Change/Chaos Theory

Part of the human condition is to seek growth and change in life while at the same time striving for order and stability. When a life-altering event such as breast cancer occurs, seemingly out of the blue without warning, the individual loses stability and faces a future of uncertainty and unpredictability. Life becomes defined as “before” and “after”
with the realization that one’s life is in crisis and will never be the same again. Chaos evokes change; the question is what kind and to what degree.

Chaos theory is considered by many postmodernists to be one of the keys to understanding individual and systemic change. Goerner (1995) posited that chaos theory could elucidate what drives change, why it is inevitable, and how order ultimately follows from chaotic circumstances. In popular usage, the term chaos implies a negative connotation, one illustrating the “savage unpredictability of the universe” (Presbury, Echterling, & McKee, 2002, p.166). Webster defines chaos as a “state of utter confusion” or a “state of things in which chance is supreme” (Merriam-Webster Online Dictionary, 2006). Chaos theory is a mathematically based theory with roots predating the ancient Greek civilization. Two premises are that chaotic events are not random, but actually are structured and orderly within their apparent disorder (Brack, Brack, & Zucker, 1995; Butz, 1995; Chamberlain, 1998; Wilbur & Kulikowich, 1995), and that there is meaning in uncertainty (Gelatt, 1995).

Since the early 1980s, chaos theory has become a new scientific paradigm used to explain different facets of various disciplines, especially the physical and life sciences. It has been used in weather forecasting, economic projections, population studies, and recently in the behavioral and social science venue. Pertinent to counseling, chaos theory is found in life-span development and learning (Duke, 1994; Levin, 2000), psychoanalysis (Frayn, 2000; Scharff, 2000), group process (Brabender, 2000; Warren, Franklin & Streeter, 1998), family and marital therapy (Ayers, 1997; Chamberlain, 1995a, 1995b), counselor education (Wilbur & Kulikowich, 1995), brief therapy (Presbury et al., 2002; Warren, et al., 1998), and alcohol abuse treatment (Ayers, 1997).
Seen by many as a domain between the “hard” and “soft” sciences, it has found support from the fields of neuropsychology (e.g., studies of epilepsy) and cognitive psychology (especially learning) (Ayers, 1997). Nursing research and practice have examined the chaos theory model of nonlinear dynamics to explain reactions to illness, and coping and adaptation behaviors by patients (Hamilton, Pollock, Mitchell, Vicenzi, & West, 1997).

Based on the mathematical principle of nonlinear dynamics but used metaphorically in behavioral science applications, chaos theory postulates that uncertainty and chaos are inherent in all systems as they interact with the environment. As a result of disruption and turbulence, different variables will work somewhat similarly to magnets, pulling a system to strive for equilibrium. Once equilibrium is achieved, the system is now in a new place; it will not return to its previous state because it has reorganized to a different level (Brabender, 2000; Brack et al., 1995). The process is nonlinear and dynamic in that there is not a direct cause/effect relationship nor is it predictable in the short time.

The behavioral science field historically has viewed change as a linear, step or phase model, occurring over time in small increments (e.g., learning theory) (Brown & Miller, 2005; C’dé Baca & Wilbourne, 2004). Chaos theory supports the possibility of rapid and dramatic change, much of which is “sudden, discontinuous” and “non-normative” (Jarvis, 1996). Quantum change, according to Miller and C’dé Baca, (2001), is an epiphany or an insight that comes in an instant flash, an “ah ha” experience resulting from a “sudden, dramatic, enduring transformation” (Miller, 2004, p. 453). This “watershed event” divides life into before and after, as in the example of Ebenezer Scrooge in Dickens’ *A Christmas Carol*. Based on actual interviews with many people...
that reported this type of change experience, Miller and C´de Baca described the resultant dramatic personality reorganizations, with an awareness of a new meaning for life, a shift in values and priorities, and new ways of thinking and being (Miller, 2004; Miller & C´de Baca, 2001).

Since breast cancer is a life-altering, random event, precipitating crisis and chaos for most, if not all, women diagnosed, I wondered what kinds of change affected women might undergo. Were there radical shifts in personality, values, and priorities, or were there dramatic transformations that followed after diagnosis and treatment? And what meaning did women make of this apparent chaos and turbulence in their lives? Therefore, I hoped to elicit stories of change in the lives of the women who participated in the current study.

Breast Cancer

Breast cancer risk increases with age. The occurrence is more prevalent in married Euro American women of higher socioeconomic status who live in urban areas of the northern United States. Although whites are diagnosed more frequently than African American women, African Americans are likely to have a more advanced stage of breast cancer at a younger age with higher mortality rates, regardless of stage at diagnosis. Filipino and Hispanic women living in the US also experience a higher rate of dying from breast cancer. Seventy-five percent of new cases occur in women over 50 years old, and 13% are in the 40-49-year-old range. When present in women under 40, breast cancer tends to be more aggressive with higher mortality rates (ACS, 2006; Keitel & Kopala, 2000). Breast cancer is correlated with education and socioeconomic status (SES), with the more educated and affluent woman diagnosed more frequently, while the
woman from a lower SES and educational background has a higher mortality risk (Baum & Andersen, 2001; Keitel & Kopala, 2000).

Cancer continues to carry with it, not only fear, but stigma and an attitude that it should have been preventable. Even in our educated and enlightened twenty-first century society, many feel that the woman herself is at fault for developing breast cancer (Brownell, 1991; Sontag, 1990). For many, the diagnosis of cancer is still considered shameful and associated with “death itself” (Sontag, 1990, p. 18; see also Patterson, 1987), notwithstanding the technological advances in treatment today. The mystery of such an illness can lead to a blame the victim mentality, especially in people espousing certain lifestyles (i.e., diet, exercise, hormone replacement avoidance) (Brownell, 1991; Haber, 1995; Janoff-Bulman, 1999; Sontag, 1990). Our confidence in medicine and science lulls us into the perhaps unconscious belief that diseases can be cured, and yet the mysterious nature of cancer often defies treatment, resulting in untimely death. Breast cancer is capricious, without definite single causation, and is likely a response to multiple risk factors in a woman’s life and genetics. Of the newly diagnosed, 95% have no family history of breast cancer, and 70% will have no known risk factors for breast cancer (Keitel & Kopala, 2000).

Breast cancer precipitates a crisis when a woman learns her diagnosis. There often is still some sense of embarrassment and shame in discussing cancer in the breasts and reproductive organs. There may be dread of disfigurement and fear of loss of sexuality and femininity, coupled with worries about the effects of treatment. Some degree of mood disorder is common, with many evidencing acute or subclinical symptoms of posttraumatic stress symptomology (Andrykowski, Cordova, McGrath, Sloan, & Kenady,
2000; Turner, 2003). It is no wonder, since breast cancer is perhaps the most
“emotionally loaded” of all cancers (Turner, 2003, p. 313), and the diagnosis catapults
the woman into the medical system, requiring her to rapidly assimilate much information.
The newly diagnosed woman has to make critical decisions without the benefit of
medical expertise and at a time of extreme emotional turbulence (Haber, 1995).

However, the good news is that survival rates for breast cancer have improved,
and current treatments have changed breast cancer from a death sentence to a chronic
illness. Breast cancer survivors are one of the largest groups of cancer survivors today
with an estimated 2.3 million worldwide in 2002 (ACS, 2006; Haber, 1995; Tomich &
Helgeson, 2002), largely due to increased early detection and mammography and to the
newer aggressive adjuvant therapies. For these women, the question becomes how to live
with a chronic illness, in which the unchanging truth is that the disease may recur. The
challenge becomes living in the uncertainty of a “new normal” of life after breast cancer.
Many women believe that diagnosis and treatment are the easy parts; the hard part is
learning to live “as if” the cancer will never return (Haber, 1995; Schnipper, 2003). For
certain, breast cancer is a life-changing experience—physically, emotionally, and
spiritually.

Breast Cancer Survivorship

Until recently, a diagnosis of cancer was equated with a death sentence. In 1930,
one in five cancer patients survived for five years (the commonly used definition of
survivor) (Carter, 1993; Thewes, Butow, Girgis, & Pendlebury, 2004), whereas by 2000,
nearly 60% were surviving (Bloom, 2002; Pelusi, 1997). Breast cancer is the most
frequently diagnosed cancer in women, and women with breast cancer are the largest
group of cancer survivors with 70-90% living at least five years (ACS, 2006; Fredette, 1995; Ganz, et al., 1996; Rothrock, et al., 2004).

It has been said that one is a breast cancer victim at the time of diagnosis but becomes a survivor when she chooses. Many view survivorship as a process, not as arriving at a discrete point in time after treatment, and the literature supports the idea of a continuum of survivorship (Carter, 1993; Fredette, 1995; Ganz, et al., 2004; Polinsky, 1994; Thewes, et al., 2004). For example, Pelusi conceptualized survivorship not as a solitary aspect of a person’s life, but as a “dynamic, life-long process” (Pelusi, 1997, p. 1353). In their “Moving Beyond Cancer Study,” Ganz and colleagues (2004, Introductory para. 1) defined survivorship as occurring once the woman has completed the acute treatment protocol and has “move[ed] beyond cancer to reestablish normal life patterns.”

What does it mean to a woman to confront breast cancer, knowing that in spite of aggressive treatment, it may recur at any time? How does one live with the physical and/or psychological sequelae of the disease and treatment? Since cancer is now conceptualized as a chronic illness, how does she adjust to a new self view as a person with a chronic illness, and how does she traverse the “health within illness” (Moch, 1995) trajectory? What does her personal identity become as a cancer survivor (Little, Paul, Jordens & Sayers, 2002)? What kind of life might she expect, and more importantly, how much control does she have over her quality of life? Such questions are beginning to be addressed in research and clinical practice, but historically the focus has been on the physical concerns surrounding the initial diagnosis and early months. Research on the longer-term impact of surviving breast cancer is still in its infancy (Carter, 1989, 1993; Ganz, et al., 2004; Helgeson, Snyder & Seltman, 2004; Tomich & Helgeson, 2002).
There is a beginning emphasis for research exploration of the psychosocial aspects of breast cancer (Carter, 1989, 1993; Ganz, et al., 2004; Woods & Earp, 1978), and how women adjust to this disease (Helgeson, et al., 2004).


After the intensity of the traumatic breast cancer experience, many survivors describe the discovery of positive growth. Tennen & Affleck (1999) define such positive changes after adversity as “benefit finding” (see also Affleck & Tennen, 1996; Sears, Stanton, & Danoff-Burg, 2003; Helgeson, et al., 2004). Some of these beneficial changes include a reappraisal of life and its meaning (Sears, et al., 2003), a new interest in spirituality (Bloom, 2002; Fredette, 1995), different goals and priorities (O’Leary & Ickovics, 1995), an enhanced sense of purpose and improved intimacy in personal relationships (Antoni, et al., 2001), and an altruistic desire to help others (Nelson, 1996).
Calhoun & Tedeschi (2006) identify this positive growth by the now widely recognized term posttraumatic growth (PTG), the “experience of significant positive change arising from the struggle with a major life crisis” (see also Calhoun, Cann, Tedeschi, & McMillan, 2000, p.521). Common PTG associated changes include existential (eg. spirituality, purpose) and behavioral (healthy lifestyle practices) adjustments. Recent research has investigated the presence of PTG in life-threatening illnesses such as myocardial infarctions, sexual assault, and adults with cancer (Manne, et al., 2004). It is only recently that PTG has been studied in relation to breast cancer survivors (Bellizzi & Blank, 2006; Weiss, 2004). Posttraumatic growth, benefit finding, and positive reappraisal appear to be “related but distinct constructs;” however, the terms are often used interchangeably in the literature (Sears, et al., 2003, p. 494).

Not all survivors identify positive growth after their experience. Consequently, there is some legitimate professional concern that counselors may inadvertently foster a client’s sense of guilt about her negative reactions to illness by the expectation that she should have found meaning or benefit. Grief, age, education, and other contextual factors may influence her perceived growth outcomes (Pryds-Jensen, Bäck-Pettersson, & Segesten, 2000; Sears, et al., 2003). There are often physical sequelae of the surgical and medical interventions the women have undergone, producing altered body-image, draining fatigue, financial strain, relational stress, and an uncertain future (Manne, et al., 2004; Taylor, 2000). Along with the physical effects are fears of recurrence and fears of dying, the two most salient and frequently verbalized concerns of women with breast cancer (Timko & Janoff-Bulman, 1985; Vickberg, 2000).
Demands of living with illness, struggling with beliefs about control and causation, adjusting to the possibility of a shortened future, and learning a survivor identity are all significant components of breast cancer survivorship. Along with these are the added concerns that impact the families of the survivors, such as role reversals and financial hardships. Although the empirical evidence would suggest that most women with breast cancer return to a somewhat stable psychological adjustment (Cordova, et al., 2001; Ganz, et al., 2004; Rothrock, et al., 2004) within the first two years or so, many women report increased symptoms of anxiety or depressed mood and existential fears of dying or recurrence (Timko & Janoff-Bulman, 1985).

Therefore, it is important that counselors working with women who are breast cancer survivors have an understanding not only of the variety of treatment protocols, but also of the after effects of treatment on the physical and the psychosocial well-being of the woman and her family (see Keitel & Kopala, 2000). Aggressive treatment has enabled more women to live with breast cancer than ever before. Yet women suffer changes in the quality of their daily lives, and they often lose their voices in the midst of the diagnosis, treatment, and survivorship experience. While many clinicians view breast cancer as a war that must be won by medicine and surgery, it is often at the expense of taking time to hear the lived experience of the survivor, who must daily negotiate the new normal life of a person with a chronic and often recurrent illness. A disease-based treatment model is no longer sufficient. It is time to hear what the survivor has to say, and to listen to what she needs. This can inform a more efficacious treatment model, returning some “sense of personal agency… to [her] quality of life” (Cihlar, 2004, p.8).
Purpose of the Current Study

The current research was a qualitative, phenomenological investigation exploring the lived experience of breast cancer survivors. Historically the focus of most breast cancer research has been on the etiology, prevention, diagnosis, and treatment concerns of the disease, typically from a medical model (Ganz, 2004; McKenna, et al., 1999; McPherson, et al., 2000). Much funding and research effort has been directed to discovering causes and cures.

Breast cancer survivorship is a more recent consideration for psychosocial research (Tomich & Helgeson, 2002), but still few have studied it from the perspective of the women who daily experience this journey for the rest of their lives (Carter, 1993; Cordova, et al., 2001; Little, et al., 2002; Pelusi, 1997; Scott Dorset, 1992; Vickberg, 2000). This study investigated breast cancer survival from the perspective of the woman who is surviving, and attempted to understand what the experience meant to her. The results in turn inform treatment interventions for those survivors we see clinically.

Furthermore, in view of the literature on change and growth (Calhoun & Tedeschi, 2004; Cordova, et al., 2001; Miller & C’de Baca, 2001; Sears, et al., 2003), this study considered what kinds of changes survivors have experienced, and whether those changes were positive or negative. Following a trauma or loss, there is an innate need to make sense of what has happened: we are meaning making people (Collie & Long, 2005; Niemeyer, 2004). New discoveries about how survivors make meaning will add to the knowledge base and to the effectiveness of treatment.
Philosophy Guiding the Research

Qualitative methodology places a “high value on the investigation of the individual’s experience” (Jarvis, 1996, p. 6) and is a method of learning about people “embedded in the context of [their] lived understandings (Carter, 1989, p. 66). Attempts to comprehend what happened, to understand and resolve it, and to search for the significance are some of the meaning making activities that individuals struggle with (Calhoun, et al., 2000; Janoff-Bulman, 2004). As meaning making humans, we compose stories about our lives and our identity. When chaotic events disrupt the life of the woman with breast cancer, her feelings and emotions begin to transform her understanding of the illness. These can become integrated into a new self narrative, as she incorporates her response to illness and trauma (Neimeyer, 2004; Pals & McAdams, 2004). Her sense of self becomes solidified through the stories she tells about herself.

Part of the growth and healing path for the survivor is to be able to share these stories that deal with her lived experience of her illness. Recently, counselors have been interested in what meanings people attribute to their illness situations, and how talking or writing facilitates this process by a symbolic use of language. As counselors, we must be sensitive and compassionate enough to be that “empathic witness” described by Kleinman, (1988, p. 54, as cited in Collie & Long, 2005, p. 847), that person able to be present with the individual and to facilitate her construction of the new illness narrative of her experience. These stories and lived experiences are referred to by Miller & Crabtree (2000) as “conversations at the walls,” a metaphorical “space” where the counselor can meet with the client, carry on a discourse or conversation about who she is and her path towards transformation, and then translate her story into clinical research
Her story and her experience elucidate the breast cancer trajectory, and better equip counselors to be therapeutic listeners to breast cancer survivors.

**Researcher Stance**

In qualitative research, the researcher is the instrument, and data collection is an interactive process between the researcher and the participant (Morrow & Smith, 2000; Patton, 2002). As such, it is important for the credibility of the study for the researcher to provide pertinent personal and professional information that might influence the research process—“data collection, analysis, or interpretation” (Patton, 2002, p.566).

Consistent with that approach, I need to share the journey that brought me to this point. Prior to commencing graduate school in counseling, I practiced as a nurse. In my public health nursing experience, I cared for an elderly woman with metastatic and fulminating breast cancer who had not received treatment due to her poverty and age. Because of the horrific smell and appearance of the abscessed area on her chest I had to struggle to look beyond the wound to see the person.

During my continued nursing assignments, I realized that I was trained thoroughly in the disease-focused medical model that espoused the primacy of the medical professional as the “expert.” I learned how to care “for” my patients. Looking back at my elderly patient, I recognized that I missed hearing her story about her lived experience of this dreadful disease.

Shortly after my return to graduate school, my very dear friend and mentor died of metastatic breast cancer. Her initial disease appeared to have been eradicated, but it recurred while she was living overseas, and she died soon after returning to the states for
further treatment. Once again, largely due to her being out of the country, I realized I had missed the opportunity to hear her story about living with breast cancer. I have learned the importance of being able to listen to the stories of the individual going through the experience, and therefore, philosophically I am comfortable with a qualitative methodology that provides the opportunity to share the lived experiences of the participants.

Morrow and Smith (2000) write about the position of the qualitative investigator as being an “insider or outsider to the population and phenomenon” (p.209). The insider stance provides the investigator and the participant the opportunity to share their culture or experience. With that in mind, I acknowledge my personal position as an insider to the phenomenon of breast cancer. I was diagnosed with breast cancer myself, and I have experienced the anxiety of waiting for the news, the fear of surgery, and the unpleasantness of chemotherapy and radiation. I am a breast cancer survivor, and I live “as if” there is no cancer while never truly escaping the knowledge that recurrence is always possible.

Contrary to much of the literature, at the time of my diagnosis, my experience with the medical team was positive and collaborative. I felt that my voice was heard and that I was the ultimate decision-maker for my treatment. Unfortunately, this is not always the case. Many women share that their doctors told them what to do, that they had difficulty getting answers to their questions, and that they were pressured to make quick decisions about treatment options that they did not understand. I have also heard stories of fears about recurrence and dying from the disease and not having anybody to talk to because they “don’t look sick.” The woman with breast cancer can become an object to
be tested and treated by those in the medical field who “know best” and want to “beat the
cancer.”

Additionally, the literature, the stories I have heard, and my own personal journey lend
credence to the aspect of personal growth and change that follows a traumatic life-
event. Miller and C’de Baca’s (2001) work on rapid transforming quantum change was
the initial catalyst for my interest in this change process after a breast cancer diagnosis. I
became curious to learn whether other women noticed changes in their lives post
diagnosis and treatment, and if so, what kinds of changes. I began listening, and I heard
about “not sweating the small stuff,” redirected life goals, spending more time with
family and friends, and a desire to serve others. This fit with my experience and with
much of the literature on survivorship, especially Janoff-Bulman’s (1999)
conceptualization of rebuilding the shattered core assumptive beliefs about the world.

For survivors, there is often a need to make some kind of meaning about the
experience of breast cancer. I personally discovered that it was useless to try to find
causes for my cancer. Instead I began questioning who I was becoming and where I
wanted to go from that point. One thing I had neglected in the frenzy of graduate school
was maintaining relationships with friends, and that is one area I re-evaluated for change.
I also had to consider what legacy I might be leaving behind if I were to die. I looked at
my relationships with close family, especially my children. I wondered if I would become
a different, more compassionate person, counselor, and counselor educator. I
acknowledged that it would be inconsistent with my development as a researcher to
utilize a quantitative methodology for my dissertation, a method of assigning numbers to
quantify a person’s suffering and a means of getting “the evidence” (Miller & Crabtree, 2000, p. 607).

I recognized that over the years I had made a theoretical paradigm shift myself, from the medical prescriptive model, to one of acknowledging that the person is the expert about her journey. Instead of promoting the power imbalance typical of a medical treatment modality, I wanted to honor women by listening to their narratives, often overlooked by clinicians.

Since more and more women are living longer after their breast cancer diagnoses, I believe they have much to teach us about being a survivor, about making meaning of the cancer, by sharing just what their lived experience has been throughout this arduous journey. I believe that as clinicians we need to hear their stories, because mental health professionals must be equipped to work with the increasing numbers of survivors.

Significance to Counseling

These stories need telling. As counselors, we are in contact with breast cancer survivors, and it is important to them to be able to tell their stories to an empathic listener. The journey of survivorship is linked to the development of their personal identities. Since counseling is a humanistic, person-centered, developmental approach that is philosophically growth-based, such stories help practitioners design more therapeutic growth-enhancing strategies for clients. Telling the story can produce the creation of a new story with new life directions for the individual. Counselors are trained to be good listeners, to be empathic, and to foster a collaborative therapeutic alliance with the client.
The predominant model for medical treatment is an expert stance on the part of the practitioner, which effectively reduces or eliminates the power and agency of the patient. The doctors “name” the disease and the treatment, and “claim the authority to name another person’s distress and to presume to know what it means for that person” to be ill (Collie & Long, 2005, p.849). This dominant discourse can block the meaning making process for the person who is struggling with breast cancer, by invalidating her feelings and her right to name her own meanings. When the clinician assumes what the woman is feeling, or pathologizes her emotional reactions to her situation, it jeopardizes her ability to create a new narrative (Collie & Long, 2005). Empathic counselors can hold those “conversations at the wall” (Miller & Crabtree, 2000, p.608) with the survivor, and facilitate her efforts at meaning making.

Additionally, there is some strong empirical support for the efficacy of breast cancer support or therapy groups, and many survivors are seeking out community groups during their recovery (Lechner & Antoni, 2004; Spira & Reed, 2003). Counselors effective in group dynamics can provide the necessary leadership and educational support for cancer centers or mental health agencies interested in serving the survivors.

Practicing from a psychosocialspiritual model, counselors are uniquely equipped to interface with the biomedical practitioners to help provide holistic comprehensive care for women with breast cancer. With greater numbers of survivors, there is the likelihood for greater mental health needs. Breast care centers and cancer treatment centers are growing in popularity, and a team model of care should include counselors to provide adjunctive emotional support and “scientifically grounded, holistically based, and…optimally effective” care (Roberts, Kiselica, & Fredrickson, 2002, p.423). The
medical model has historically utilized social workers within the hospital setting. Social workers are highly trained professionals who assist patients with accessing community resources. Counselors, however, would be a tremendous asset to the woman by helping identify her mental health needs during her breast cancer journey, and by advocating for her within her family and her medical team.

Given the small number of studies investigating the lived experiences of the woman with breast cancer, this study expands the theory and knowledge of what that experience is, and what the women themselves consider important about changes in their lives after a breast cancer diagnosis. The application of the knowledge gained from the research enhances the clinical understanding and skills of the counselor who works with survivors. Since one of the possible mediators of posttraumatic growth is the opportunity to share personal narratives with willing listeners, the counselor must be equipped to validate the survivor’s story and facilitate healing growth (Calhoun & Tedeschi, 2004; Neimeyer, 2004). The opportunity to answer the questions “so what?” and “then what happened?” improves the lives of the survivors themselves.

Chapter I Summary

The focus of the current research was to consider how women with breast cancer understand their lives. The specific aim was to determine whether or not they have undergone changes in their lives as a result of their diagnosis and treatment, especially positive changes that elucidate new benefits or meanings to life. The methodology used was qualitative, from a phenomenological and narrative perspective that listens to the stories of the participants’ lived experiences as breast cancer survivors.
This study expanded the literature on counseling with breast cancer survivors by addressing the research gap surrounding the occurrence of quantum or epiphanic change, posttraumatic growth, and meaning making in the lives of survivors. Although not all change will be positive, there is support that for many survivors benefits occur after the diagnosis of cancer with changed lives as a result.

The following chapter will present a broad review of the literature that informs the foundation for the current research.
CHAPTER II
THE LITERATURE REVIEW

Introduction

“All sorrows can be borne if we can put them into a story.” Isak Dinesen

The objective of the current research was to understand how breast cancer survivors make meaning of the changes in their lived experience of dealing with their disease. The term “lived experience” has a connotation to the qualitative researcher that signifies that part of the survivor’s life that makes up her “lived world of everyday experience” (Riessman, 1993, p. 8). Only as she then tells the story about the experience can the researcher link the understanding and interpretation with the experience. Unable to have actual direct knowledge of the experience, the researcher has to rely upon the survivor’s expression of parts of the actual story: those parts she selects to story. As she tells stories, she and the listener begin to organize, interpret, and understand the meaning of the experience as it evolves (Brown & Augusta-Scott, 2007; Josselson, 1995).

The purpose of the literature review is to establish a framework for the research by identifying and analyzing the existing studies addressing the topic area. Previously completed research will elucidate gaps in the literature and aid in uncovering future research directions: the “next steps” for furthering the knowledge base (Creswell, 2003;
Heppner & Heppner, 2004). The subsequent review lays the foundation for the research of this study.

The first section of the literature review provides an overlying conceptual understanding of the process of change during the breast cancer trajectory. Included in this section are basic concepts of chaos theory that apply to the idea of breast cancer as a random, life-altering event of uncertainty, provoking change and reorganization (Brabender, 2000; Goerner, 1995). Quantum change, an epiphanic, rapid, and dramatic life change (Miller & C’ de Baca, 2001) is also considered in the context of the survivor who may undergo personal transformation, revised priorities, and new ways of being.

The second section discusses breast cancer from the standpoint of the survivor. It includes explanation of risks, fears, treatment options, and long-term physical and psychosocial effects. With breast cancer now considered a chronic illness rather than a death sentence, the chronic illness experience and alteration of the survivor’s identity while adapting to the “new normal” of life will be addressed (Charmaz, 1995, 1999a, 1999b; Cihlar, 2005). Additionally, the possibility of posttraumatic stress symptomology and posttraumatic growth, the re-evaluation of core assumptive beliefs about the world, and the potential for positive change as a result (Calhoun & Tedeschi, 2006; Carter, 1993; Janoff-Bulman, 1999; Tennen & Affleck, 1999) are considered.

The final section reviews the concepts of meaning making as the survivor defines a new narrative about her life. Breast cancer is an experience of grief and loss that may or may not be accompanied by some perception of gain, and the grieving individual strives to make sense of loss through searching for a unique personal story that incorporates her
illness into her life (Collie & Long, 2005; Neimeyer, 2004). Part of the cognitive restructuring that occurs within the experience of a life-threatening illness is the need to go beyond the questions of why and begin to grapple with personal meaning and the need to “be,” a sense of having health within illness (Moch, 1995; Taylor, 2000).

The final part also includes a discussion of narrative theory as it applies to the stories survivors organize for making sense of breast cancer’s disruption of their lives, and how they reconstruct a new and coherent self identity (Riessman, 1993). Information about narrative analysis is further developed in the discussion about the qualitative research methodology in Chapter III.

Change

The idea of change has long been a cornerstone of counseling theory. If counselors did not believe that people were capable of changing, there would be little point in our clinical practice. Change has characteristically been described as occurring in increments (usually small), over time (often long), with a back and forth, peak, valley, and plateau type of pattern, a series of small approximations to reach the hoped for end result. It is recognized that change can occur within, between, or even without therapy sessions (Tallman & Bohart, 1999), and paradoxically it is one of the inevitable constants in our world (Goerner, 1995; Miller & C’d Baca, 2001; Nielsen, 2001).

Change is typically described as a linear or stage model related to learning and reinforcement (Brown & Miller, 2005; C’d Baca, Wilbourne, 2004; Miller & C’d Baca, 2001), and that conceptualization has been the primary focus of psychotherapeutic understanding and practice (Jarvis, 1996). Yet it can also be a dramatic and sudden
transformation within a short time, a “watershed” event (Miller, 2004; Tallman & Bohart, 1999). Such a model describes nonlinear and discontinuous change that may be considered a type of epiphany or a sudden and dramatic revelation that something is different (Jarvis, 1996). Often associated with spiritual conversion, this phenomenon was first acknowledged and investigated by William James at the beginning of the 20th century (James, 1902, as cited in Miller, 2004). Such nonlinear, possibly epiphanic types of change that may be part of the breast cancer survivorship journey are the focus of the current study.

Chaos Theory

James Yorke introduced the idea of “chaos theory” in his 1975 paper on Edward Lorenz, the meteorologist who developed a computer program in the 1950s in an attempt to predict the weather. Lorenz coined the phrase “butterfly effect” or “sensitive dependence on initial conditions” to explain his findings that even miniscule fluctuations in environmental conditions could produce large scale alterations in the weather (Butz, 1995, p.84; Gleick, 1987, p.23). Lorenz’s computer model attempted to predict consistent weather patterns, but as a result of rounding off small decimal points in the mathematical equations, the predictability was inaccurate. The nickname butterfly effect alluded to the possibility that a fluttering butterfly in Beijing might alter future storm systems in New York (Gleick, 1987). The principle is that tiny changes can produce major effects by disrupting the entire system (Chamberlain, 1995b).

In actuality, chaos theory is not new at all, but predates the ancient Greek civilization. Butz (1995), one of the leading authors about the application of chaos theory
to psychology, provided a brief historical review of the presence of chaos in the creation mythologies of Asian, Egyptian, Greek, and Native American cultures. He maintained that these ancient and nonwestern peoples were much more comfortable with the concept of nonlinearity and chaotic existence than those of European descent. In current scientific and psychological methodology, however, the positivistic linear approach to data has been the standard, and any data outside the agreed bounds of order is considered bad data or noise. Scientists either attempted to explain chaotic systems by a linear model or avoided them altogether (Butz, 1995).

In the early 1970s, scientists seeking to uncover relationships among irregular physical systems, such as the heart and circulatory system, began talking about chaos theory as a new paradigm (Collett, 1998). Gleick is credited with its recent popularity, and he differentiated it from the classical sciences of mathematics, physics, and biology. Chaos theory is a nonlinear “science of process rather than state, of becoming rather than being” that does not analyze constituent parts, but rather looks at patterns and the whole (Gleick, 1987, p. 5). Two basic premises of chaos theory are that chaotic events are not really random, but instead have order within apparent disorder (Brack, et al., 1995; Butz, 1995; Chamberlain, 1998; Wilbur & Kulikowich 1995), and that there is meaning in uncertainty (Gelatt, 1995).

Chaos theory is based on the mathematical principle of nonlinear dynamics which describes a relationship or system that is paradoxical and unpredictable. Small degrees of input or change may result in wide variations of output (i.e., the butterfly effect), attributable to the multitude of interconnected relationships (Collett, 1998). There is no
direct cause and effect relationship, nor is there a degree of predictability in the short time
(Chamberlain, 1995b; Goerner, 1995). As a system interacts with the environment, the
resulting disruption and turbulence function similarly to magnets, drawing the system to
seek equilibrium. During the process, the system reorganizes and essentially may
reconstruct itself into a new pattern or organization. The system, unable to return to its
original state, instead rearranges into a new level (Brabender, 2000; Brack et al., 1995;
Wilbur & Kulikowich, 1995). Such a reorganization and striving for equilibrium have
implications for counseling given that clients may appear to be in chaotic states when
they seek professional mental health services. Specifically, when the diagnosis of breast
cancer catapults the woman into a state of chaos, the combination of treatment
approaches, her medical team, her support system, and other personal resources become
the magnetic attractors, drawing her to seek a return to stability and equilibrium.

Chaos theory posits that although “long-term predictability is impossible” (Brack,
et al., 1995, p. 200), underlying the apparent randomness of change is some form of order
and pattern, albeit not necessarily linear or controllable (Butz, 1995; Collett, 1998). Since
unpredictable change is part of the natural law, a logical counseling implication would be
to assist clients to adapt to the everyday changes occurring in life, rather than trying to
maintain rigid control. Again, the cancer victim has to adjust rapidly to a state of
uncertainty, and it soon becomes apparent that there is no return to the “before.”
Flexibility, not additional control, may be a more healthy response to such turbulence and
hopefully will lead to growth, not disintegration (Brack, et al., 1995). Butz maintains that
“healthy systems ‘dance’ between being too rigid and too chaotic, and that systems that
are too rigid will die out” (Butz, 1993, as cited in Brack, et al., 1995, p. 204). Hence, a
counselor needs to support the person going through the anxiety of chaotic experiences
and encourage flexibility, or conversely, the clinician may find it therapeutic to plan
interventions that “stir the pot” in a client who may be stuck, producing some turbulence
in an attempt to foster disequilibrium and change.

Since the early 1980s the tenets of chaos theory have been utilized in various
disciplines, such as weather forecasting, population studies, and economic forecasting.
Seen by many as a domain between the “hard” and “soft” sciences, chaos theory has
found support in the fields of neuropsychology (e.g., in studies of epilepsy) and cognitive
psychology (especially learning) (Ayers, 1997). Nursing research was one of the early
domains to adapt chaos theory and nonlinear dynamics in explanation of certain
population trends and epidemiological findings, as well as adaptive coping behaviors and
patient reactions to illness (Hamilton, et al., 1997). In the behavioral and social science
fields, chaos theory is most generally used metaphorically, postulating that uncertainty
and chaos are inherent in all systems as they interact with the environment. Chaos theory
has made inroads into life-span development and learning theories (Duke, 1994; Levin,
2000) and alcohol abuse treatment (Ayers, 1997). Relative to counseling, chaos theory is
apparent in the arena of counselor education (Wilbur & Kulikowich, 1995), marital and
family therapy (Ayers, 1997; Chamberlain, 1995a), psychoanalytic therapy (Frayn, 2000;
Scharff, 2000), brief therapy (Presbury et al., 2002; Warren, et al., 1998), and in group
process (Brabender, 2000; Warren et al., 1998).
In the psychological literature from 1994 to about 2000 there was some degree of interest regarding the adaptation of chaos theory to psychosocial interventions (see Butz, 1995; Chamberlain, 1995a; Chamberlain, 1998; Duke, 1994). Additionally there were a few related doctoral dissertations (see Collett, 1998; Frank, 1997; and Jarvis, 1996). However, the interest apparently has faltered, as there are few studies after the late 1990s (exceptions include Brabender, 2000; Frayn, 2000; Levin, 2000; Procci, 2002). Frank’s (1997) dissertation compared and contrasted chaos theory with Gestalt therapy and creativity theory. Jarvis (1996) considered epiphanies, the “ah ha” type of change, in the context of systems theory, and found support for the possibility of positive change following random turbulence in family systems. This finding, in contradiction to the conventional thought that chaos is negative, described chaos theory as sustaining the possibility of rapid, dramatic change which is positive, although discontinuous and nonnormative (Jarvis, 1996).

Collett’s (1998) investigation of how participants found meaning in response to serious life-altering events, such as terminal cancer, spousal abuse, and traumatic brain injury, applied “chaos theory to people in crisis” (p. 42). Based on Frankl’s theoretical conceptualization of meaning and logotherapy, Collett defined the human condition as including that “ability to change and reshape ourselves based on our experiences” and our penchant for assigning meaning to the events that occur in our lives (Collett, 1998, p. 27). Believing that our perceptions in fact shape the reality of our lives, accepting and adapting to chaotic changes of life allows for the possibility of growth, not bitterness.
Looking for linearity, prediction, or control is not helpful in moving beyond the chaos to attain meaning for one’s life. Embracing the resultant change instead fosters growth.

After accepting the end of the once familiar, pre-crisis way of life, part of the healing process includes reviewing memories of the event and telling stories about it (Collett, 1998; see also Niemeyer, 2004). Collett found that participants “looked beyond the event” and thus “found greater meaning in their lives” (1998, p. 125). Positive attitudes, supportive people, and the formation of new meaningful connections helped the individuals in the study.

Quantum Change

Quantum change (QC) has been defined by Miller and C’de Baca (2001) as an epiphany or sudden insight that comes in a flash. It is an “ah ha” experience resulting from a “sudden, dramatic, enduring transformation” that happens in a twinkle (Miller, 2004, p. 453). James, considered the founder of American psychology, pioneered a study of two different types of change: the typical gradual stepwise movements towards change and the sudden, discontinuous phenomenon widely known as transformative change (Miller & C’de Baca, 2001). The latter change was commonly reported by those experiencing spiritual transformations, such as Gandhi, the Buddha, St. Paul, and Martin Luther, and social activists including Florence Nightingale, Malcolm X, and Bill Wilson.

Literature and film have also been rich with examples. Ebenezer Scrooge from the classic tale by Charles Dickens, A Christmas Story, was one character who experienced this type of watershed event after the visits by the Christmas ghosts, dividing his life into the before and after (Miller & C’de Baca, 2001). Bidney, a comparative literature
professor, described literary epiphanies as quantum changes in the lives of Fyodor Dostoevsky and Leo Tolstoy, 19th century Russian novelists. Tolstoy’s quantum change was a type of religious conversion at a time of suicidal despair. Tolstoy alleged the change was permanent, stating “the light did not again abandon me” (Tolstoy, 1940, pp. 64-65, as cited in Bidney, 2004, p.476). Dostoevsky’s experience was more dramatic. As a member of the gentry, he was accused of a crime and was in line awaiting execution. At the last second, when the rifles had been raised and cocked, a pardon from the Tsar arrived, sparing Dostoevsky’s life. He reported the “vanishing of all hate and anger…nothing less than a ‘miracle’” (Bidney, 2004, p.474). Bidney claimed that this change was also lasting, and that it was documented in Dostoevsky’s novel *The Brothers Karamazov*, written in 1880. Another example, this one from film, was the character George Bailey, in Frank Capra’s *A Wonderful Life*. Despairing, George was ready to jump off a bridge when at the last instant, he was inexplicably transformed and saved (Miller & C’dé Baca, 2001).

In the 100 years since the works of James, psychology has demonstrated little interest in this phenomenon of sudden transformation (Miller & C’dé Baca, 2001). Although historically, theology was the ancestor of psychology, and James was writing at the time when the two fields were closely aligned, psychology later focused on rational empirical data, veering away from spiritual experiences. Consequently, Miller and C’dé Baca initially found most of the information on quantum change in theological writings. Once they began looking for real life stories of people who had undergone this transformative change, they discovered that many conversions do not have permanence,
and that quantum change is a “larger phenomenon than religious conversion” and includes more unique attributes than conversion (Miller & C’de Baca, 2001, p. 7).

Miller and C’de Baca (2001) interviewed people in 1989 who reported stories of quantum change, and they were persuaded that these accounts were not only real but common occurrences. One of the consistent questions they asked the interviewees was what was different in their lives after the experience. Although in the interviews most of the reports were about positive changes, there were some instances of negative aftereffects. However, there were nearly universal descriptions of dramatic personality reorganizations, with awareness of new meanings for life, shifts in values and priorities, and different ways of thinking and being (Miller, 2004; Miller & C’de Baca, 2001).

True quantum change has four fixed attributes. The first is vividness, an obvious (to the person) knowledge that something profound and extraordinary has happened. This is usually almost instantaneous, but some individuals reported it occurring over a few hours or a few days. It is often associated with a specific time and moment, and may include a vivid sensory memory. A second characteristic is surprise, unannounced and uninvited. Benevolence is another quality. Those experiencing QC described an overwhelming sense of goodness and love, even when the experience itself was not a pleasant or positive one. Joy, relief, and elation were typical accompanying emotions (Bidney, 2004; Miller, 2004; Miller & C’de Baca, 2001).

Permanence is the final attribute, a “one-way door through which there is no going back” (Miller & C’de Baca, 2001, p. 5). Even twenty years later, the original interviewees acknowledged that the changes had not only endured, but had “expanded
and evolved” (C’dé Baca & Wilbourne, 2004, p. 538). Drawing on their experience with chemically dependent clients, the authors remarked that permanence is atypical of the more traditional change process (Miller & C’dé Baca, 2001).

One dissenting voice to the suddenness of change in QC is Bien, (2004), who stated that typical psychotherapeutic change is more gradual, even though it was still a type of quantum change. Bien’s claim that the lack of suddenness of onset may simply reflect different perceptions, and that while change is occurring continuously and out of sight, it may be dramatically and rapidly manifested at a unique point in time. Bien supported the other three qualities of quantum change, however, and encouraged clinicians to facilitate this process of QC in their clients. Bien’s admonition to not try to solve a client’s dilemma but to support the client in the experience seems similar to allowing the turbulence of chaos to draw the person to a new equilibrium (Bien, 2004).

Quantum change is also not limited to discrete personal qualities, but apparently provokes complete personality reorganization when it occurs (C’dé Baca & Wilbourne, 2004). It alters core beliefs and the individual’s style of perceiving reality. A totally different sense of self results from the disruption of how a person makes sense of life. Janoff-Bulman (1999, 2004) addresses this process in her work on the shattering and then rebuilding of core assumptions following trauma. Perhaps this is similar to the self-actualization experience described by Maslow and humanistic psychology (Miller & C’dé Baca, 2001).

There are two types of quantum change described by Miller and C’dé Baca (2001). The insightful type is a new understanding or realization, often described as an
“ah ha” experience in which the person suddenly “gets it”. Immediately the person is confident of the truthfulness of the insight which may have grown out of the life experiences or even psychological processes that have been ongoing over time (Miller, 2004; see also Bien, 2004). The other QC is of a mystical nature, complete with a “noetic sense of being acted upon by something outside and greater than oneself” (Miller & C’dé Baca, 2001, p.21). This type is usually more sudden, more dramatic with a comprehension that life will never be the same again. It is likely that in reality the two types are part of a continuum and not necessarily discretely different, and both would seem to foster changes in the ways the person views others, the world, and the self (Miller & C’dé Baca, 2001).

Interviewees of the original study commonly reported major shifts in life values and priorities after their QC phenomena. Material goods were less important while family and relationships assumed more value. At the core, their very identity was transformed with an altered sense of self. Some in the group had experienced a crisis or had hit the bottom, but not all were in distress. Regardless, the experiences seemed to be consistent across individuals with similarities appearing in worldviews, almost as if they had all “glimpsed the same truth” (Miller, 2004, p. 458).

Breast Cancer

Quantum change intrigued me as I considered the survivor of breast cancer. Breast cancer is an apparent random event, precipitating crisis and chaos, and resulting in a turbulent state of disequilibrium. I wondered what types of changes women experienced as they negotiated the cancer journey. Lifshitz, in the preface to a book of poetry by
breast cancer survivors, described change as cataclysmic, the kind “that drops like a death sentence and forces us into being who we are not” (Lifshitz, 1988, p. xvii). Further, I questioned whether or not survivors might undergo dramatic personality reorganization or shifts in perspective after diagnosis. I believe that a conceptualization of the survivor that includes an understanding of chaos and quantum change is an important area to investigate. Additionally, the breast cancer literature supports similar findings of reappraised purpose and meaning (Sears, et al., 2003), changed priorities (O’Leary & Ickovics, 1995), and deepened relationships (Antoni, et al., 2001).

**Breast Cancer Facts**

The day following the Presidential election of 2004, Elizabeth Edwards, the wife of the defeated candidate for Vice President, announced to the nation that she had just been diagnosed with breast cancer. In her poignant autobiographical story she remarked, “This time yesterday, we’d been winning the election and I’d been healthy. Today, we had lost and I had breast cancer [sic]” (Edwards, 2006, p. 18). Recently several other well-known individuals have been diagnosed with breast cancer; for example, Laura Ingraham, radio celebrity, and Melissa Etheridge and Sheryl Crow, rock musicians. These women have bravely made their battles public, hopefully raising awareness for the rest of us about prevention, early detection, and treatment. Such openness is quite a contrast with the conspiracy of shameful silence that was once the norm for victims of breast cancer. Breast cancer was embarrassing, mysterious, and private when, just a mere generation ago, Shirley Temple Black and Betty Ford shocked the nation by publicly announcing their breast cancer diagnoses. More importantly, as recently as the 1970s,
breast cancer was so stigmatized that doctors were loathe to give too much information to their patients, because it was considered too scary (Patterson, 1987).

One in eight women in the US will hear the words “You have breast cancer,” which translates to over 200,000 women who were diagnosed in 2003, and a projected 213,000 women for 2006 (ACS, 2006; Ganz, et al., 2004). Breast cancer is the most common cancer diagnosis in women, and it is the “most emotionally loaded of all the cancers” (Turner, 2003, p. 313). Second only to lung cancer in mortality rates for women, 41,000 women are expected to die from breast cancer in 2006 (ACS, 2006). Age increases the risk, with 75% of new cases occurring in women over 50; therefore, the aging demographics of the US make it likely that the overall numbers will continue to rise. Additionally, demographics show higher risk in the poor urban African American, Hispanic American, and Filipino American women, who are typically diagnosed later and with a much more aggressive cancer resulting in higher mortality rates (ACS, 2006; Jemal, et al., 2003; Keitel & Kopala, 2000).

The current understanding of breast cancer is that it is a capricious and insidious multifactorial disease, involving the “interaction of genetic, immunological, psychosocial, and environmental factors” (McKenna, et al., 1999, p. 520). There is no known cause, nor is there any guaranteed cure (Keitel & Kopala, 2000). Conventional wisdom supports the belief that if a woman has no family history for breast cancer and is faithful with breast self examinations, she is safe. Unfortunately, medical science and actual statistics contradict this: by the time a lump is felt, the cancer is thought to have been present for eight to ten years, and 90-95% of newly diagnosed women have no
family history, while 75% have no known risk factors (Keitel & Kopala, 2000; McPherson et al., 2000).

Risk factors commonly thought to be associated with development of breast cancer are varied. Age and being female are the two most highly correlated (Haber, 1995). However, men are not immune, and the incidence of breast cancer in men and also in younger women is increasing (ACS 2006). In premenopausal women diagnosed with breast cancer, approximately 10% will test positive for the BRCA1 or 2 genetic mutations, and a greater percentage will be Ashkenazi Jews (breastcancer.org, 2006, April 19).

Other possible risk factors include prolonged exposure to female hormones by experiencing early menarche, late menopause, nulliparity or late age at first pregnancy, or by using hormone replacement therapy (Haber, 1995; McPherson, et al., 2000). Conflicting findings surround lifestyle behaviors such as diet, exercise, weight history, alcohol use, and smoking (Keitel & Kopala, 2000; McPherson et al., 2000). The family history connection correlates with greater incidence in women who have first degree relatives (mother or sister) with breast cancer, especially when genetic studies confirm the presence of the mutated BRCA 1 or 2 genes. Considered an “autosomal dominant gene with limited penetration,” BRCA 1 or 2 may be present in a person without the development of breast cancer, but the risk of cancer increases when the afflicted relative was younger than 50 years old at diagnosis (McPherson, et al., 2000, p. 27).

Geography and environmental toxins may also play a role. Urban areas seem to have greater incidence, especially in the northeastern US. Countries in the far east have
rates five times lower than western countries such as the US or the United Kingdom, and yet migrants from eastern countries appear to approximate rates of the host countries within a couple generations, supporting the likelihood that an environmental or lifestyle factor may be a greater risk than heredity (McPherson, et al., 2000).

For years there has been speculation that there might be a “cancer personality” susceptible to emotional stress, repressed emotions, and self hatred (Patterson, 1987). It is also not uncommon for breast cancer survivors to attribute stressful life events to their development of breast cancer, and conversely to believe in the efficacy of a positive attitude for prevention of recurrence (Stewart, et al., 2001). However, there is no firm empirical support for these opinions. In a meta-analysis of over 100 articles, McKenna, et al., (1999) found that there is strong support for biologic factors but only modest support for psychosocial factors in the development of breast cancer.

Unfortunately, even today in our educated, enlightened society, there can still be a stigma associated with the diagnosis of breast cancer. Sontag described cancer as being associated with “death itself” in the classic, *Illness as Metaphor*, (1990, p. 18). Writing nearly fifteen years later, Brownell, known for coining the term “yo yo dieting,” described the common attitude that we think we have control over our health by our choices of certain healthy and right behaviors, such as positive attitudes, stress reduction, diet and exercise. With the belief that if we take the right actions we can stay healthy, it therefore logically follows that ill health comes from irresponsibly choosing the wrong actions (Brownell, 1991; Stewart, et al., 2001). There is a significant yearning to attribute psychological causation to physical illness, because then surely we can “choose not to be
sick or die” (Stewart, et al., 2001, p. 182; see also Sontag, 1990). Such moral overtones have fostered a blame the victim attitude that breast cancer should have been preventable, and that the woman is somehow at fault for developing this disease (Brownell, 1991; Patterson, 1987; Sontag, 1990).

However, the good news is that survival rates for breast cancer have improved as a result of newer, more aggressive adjuvant treatments and earlier detection with mammography. There has been a significant decrease in deaths between 1990-2002. Depending upon the source, estimates of women living longer than five years post diagnosis range from 70-98%, making breast cancer survivors the largest group of cancer survivors (ACS, 2006; Fredette, 1995; Ganz, et al., 1996; Rothrock, et al., 2004).

Breast Cancer Survivors

Des Pres (1976) interviewed individuals who survived incarceration in the concentration camps of Nazi Germany and the former Soviet Union, and defined survival as that capacity to live beyond the horror of suffering and evil, “beyond fear and despair” (as cited in Carter, 1989, p. 312), while remaining sane and human. Des Pres extols the necessity of not trying to remain detached or clinical scientists, but of looking at suffering and surviving within the context of the survivor’s perspective and by allowing survivors to tell their own stories (Des Pres, 1976). This philosophical underpinning resonates with the need for clinicians to hear the stories of the breast cancer survivors within the context of their daily lived experience of cancer.

The common yardstick of cancer survival has been five years past diagnosis, although breast cancer can recur at any time, even years beyond the five year mark.
(Neilsen, 2001; Schnipper, 2003). Cancer, formerly viewed as always fatal, is now more aggressively treated with newer adjuvant therapies, and many survive. In 1930, just one in five cancer patients lived for five years (Carter, 1993; Thewes, et al., 2004); by 2000, nearly 60% were surviving (Bloom, 2002; Pelusi, 1997). In 2002, the most current year for NCI survival statistics (ACS, 2006), there were an estimated 2.3 million breast cancer survivors worldwide (Haber, 1995; Tomich & Helgeson, 2002).

Cancer has been such a huge public health crisis and the major cause of “premature mortality” (Baum & Anderson, 2001, p. 3; Jemal, et al., 2003) that metaphorically it became a war to be won at all costs, with physicians as generals intent on wiping out the enemy that is cancer (Patterson, 1987). Consequently, the focus of research was on etiology, treatment, and prevention. Researchers and doctors were less interested in the psychosocial aspects, since the goal of the mission was to kill the disease. When psychosocial research was conducted, it primarily considered the early phases of diagnosis, surgery, and initial treatment as prognosis for long term survival was guarded (Tomich & Helgeson, 2002).

When a woman is diagnosed with breast cancer, the all too common scenario is that of a woman in “perfect” health, who in a few short months becomes ill, not from the disease, but from the treatment. Breast cancer treatment is invasive, aggressive, and not without physical and emotional sequelae. Surgery is only the beginning of a major onslaught against the integrity of her body. During the active treatment phase, however, most women feel protected by the medical team as a consequence of the nearly constant surveillance. Once completed, it is likely that the real crisis begins. The prior treatment
time for many feels like the “easy part” (Schnipper, 2003, p. 14). The real crisis now becomes living daily with the after effects, without the prior close medical supervision, and in a sense of a “new normal” (Charmaz, 1999a, 1999b; Turner, 2003).

The survivorship trajectory of women with breast cancer is just recently surfacing as a research interest (Tomich & Helgeson, 2002). Most studies have been quantitative in nature (Ganz, et al., 1996; Ganz, et al., 2004; Helgeson, et al., 2004; Rothrock, et al., 2004; Tomich & Helgeson, 2002), and have investigated emotional well-being, depression and anxiety, fears of recurrence (Ganz, et al., 2004; Rothrock, et al., 2004), as well as the possible presence of post traumatic stress symptoms (Andrykowski & Cordova, 1998). Ganz, et al., (2004, Introductory para. 1) defined survivorship as that state of “moving beyond” the initial acute treatment protocols and resuming some sense of a normal life post breast cancer.

Cancer is conceptualized by some (Cordova, et al., 2001) as a psychosocial transition, a significant occurrence that “requires individuals to ‘restructure [their] ways of looking at the world and [their] plans for living in it’” (p. 176). Unfortunately, for many survivors, the expectation from others has been that once the active treatment is completed, the survivor is back to normal and should simply move on. This all or nothing, ill or cured mentality seems to be common. However, Pelusi (1997), conceptualized survival as a “dynamic, life-long process” (p.1353), rather than a set of discrete points in time after treatment (Carter, 1993; Fredette, 1995; Ganz, et al., 2004; Polinsky, 1994; Thewes, et al., 2004). The survivor not only continues to adjust to
physical changes, but also is actively experiencing existential tensions of confronting mortality and reevaluating life (Cordova, et al., 2001; Little, et al., 2002).

Little, et al., (2002) studied the phenomenon of survivorship identity. They stated that illness is something understood in the stories of our culture, and persons with cancer have a legitimate illness identity. Others know how to relate to them, because there is acceptance and understanding for someone who is ill. However, the process of surviving alters and disrupts the person’s personal identity, that sense of personhood that positions us within the social context and defines our roles. It seems that cancer survival is so recent, that the identity is still evolving, and people do not quite know what roles to assume as the survivor.

Carter’s (1989) dissertation was one of the earliest studies to consider the prolonged effects of breast cancer survivorship. Interestingly, one of the salient findings was that there needed to be more studies reporting on the long term psychosocial aspects of survival; and in 2004, Ganz and colleagues made the exact same point. Additionally, Carter’s study was one of the initial studies to investigate the lived experience of survivorship from the perspective of the woman with breast cancer, and many of the other early studies considering the survivors’ lived experience also came from nursing researchers (Carter, 1989, 1993; Coward, 1990; Fredette, 1995; Pelusi, 1997; Quint, 1963, 1964; and Wyatt, Kurtz, and Liken, 1993).

Breast cancer has an overwhelming emotional impact on women (Timko & Janoff-Bulman, 1985). Fears of recurrence (Vickberg, 2000), altered relationships, fatigue, changed body image and possible sexual concerns (Taylor, 2000), economic
hardships, and interrupted future plans (Gordon, et al., 2002) are just a few examples of aftereffects. However, with improved survival rates, it is too easy perhaps to overlook the very salient issue of mortality: the fear of recurrence and possible death by cancer accounts for the primary concerns of affected women (Timko & Janoff-Bulman, 1985; Vickberg, 2000).

Chronic illness experience

Breast cancer is now recognized by health professionals as a chronic illness, with episodes of prolonged remission and possible recurrences (Scott Dorsett, 1992). However, little of the chronic illness literature is specific to breast cancer (see Gordon, et al., 2002; Packard, Haberman, Woods, & Yates, 1991). One definition of chronic illness is an illness that lasts longer than three months, but chronicity is more than just a dimension of time. Other factors are its interference with the person’s physical or social functioning, the degree of permanence versus possible reversibility, and the regimen of symptom management. It may be incapacitating, life-shortening or fatal, progressive or unchanging. By common agreement, however, chronic illness is one that is incurable, with a lasting impact on the person and the family and without any hope of the person’s return to a pre illness state of health (Sidell, 1997). The individual’s “sense of identity and human integrity” have been assaulted (Roberts, et al., 2002).

The fears of living with a chronic illness and its demands on oneself and one’s family often are worse than the fears of dying. Financial depletion, relational strain, role reversals, and fears of abandonment may occur. Fears of losing independence or of
becoming a burden are common (Manne, et al., 2004; Roberts, et al., 2002; Taylor, 2000). Medically managing the illness and the symptoms can become a full time task.

Chronic illness is accompanied by a sense of loss and a sense of betrayal by one’s own body (Gordon, Feldman, & Crose, 1998; Siddell, 1997). As is typical with threatening events, the woman seeks to find a meaning for the cancer to help her achieve a sense of mastery and control over her well being (Taylor, 1983). The unpredictability of breast cancer and the constant possibility of a recurrence are articulated in Mishel’s model of the “perceived uncertainty in illness” (Mishel, 1981, p. 258, as cited in Livneh & Antonak, 2005, p.13). There are no guarantees, and the question becomes how to live in the shadow of such uncertainty.

Charmaz (1995, 1999a,1999b) discussed how a chronic illness assaults the individual’s body, undermining the sense of physical wholeness and proving that the woman can no longer take her body for granted. In a ten year longitudinal qualitative study of 55 chronically ill people and 20 caregivers, Charmaz investigated the effects of the chronic illness experience on the self. One of the significant findings was that the actual concept of the self lags behind changing experiences, and that the person views the pre illness self as the “real” self, and will unknowingly assume that her future self will be that same old self. As the woman comes to grips with her illness, she has to reappraise the self within the discovery of the permanence of the change and mourn the loss of the former self.

Part of the emotional reappraisal and rebuilding of the self includes recognition of a sense of loss. Hopefully that will be followed by resolving the loss and hurt and the
ability to see oneself from a new perspective. Ideally, she would then experience a sense of growth and a positive view of her strengths, and as she learns to live with her illness, renewal and transcendence of deepened meaning of life are possible. She becomes a new person with new values (Charmaz, 1999a, 1999b).

Charmaz (1999b) identified three stages of adjustment to repeated losses and interruption of daily life. The first stage is to come to grips with an altered experience of a body which feels alien and no longer meets the “cultural standards of ageless perfection” (p.98). Part of the difficulty is that a woman with breast cancer does not always look ill (exclusive of the visible hair loss that accompanies chemotherapy), nor does she have an obvious physical infirmity. However, the loss of a breast (or in the case of breast conserving surgery, an altered shape), plus her loss of hair, eyebrows, and lashes, definitely contradict the cultural feminine ideal. One of the aspects of this stage is an objectification of the body as something that needs to be fixed (Charmaz, 1999b).

Since self concept is so closely linked to body image, a visibly altered body leads to a change in self identity, as well as in one’s future identity. The risk is that others will define the woman by her illness, and she will define herself exclusively by her less than perfect body. In the final stage the woman ideally relinquishes fighting for control over her illness. Instead, she begins to accept the illness experience, knowing that adjustments will occur repeatedly over time (Charmaz, 1995, 1999a,1999b; Little, et al., 2002).

Posttraumatic stress and shattered assumptions

A breast cancer diagnosis is considered a potential life threatening illness, which now meets the criteria for posttraumatic stress disorder (PTSD), according to the DSM-
The extreme stressors of fear of loss of life, the aggressive treatment that threatens the integrity of self, plus the intense fear of helplessness are all justification for a PTSD diagnosis. The clusters of symptoms characterizing PTSD include reexperiencing the trauma of the diagnosis or treatment (flashbacks or nightmares), avoidance of trauma reminders (noncompliance with treatment, numb affect), and hyperarousal (irritability, sleep disturbance, exaggerated startle) and have been documented in breast cancer survivors (Andrykowski, et al., 2000). The intermittent medical procedures of treatment and follow up with repeated exposure to fears of recurrence may exacerbate the “wax and wane” pattern of the symptoms (Andrykowski, et al., 2000, p. 70). Andrykowski and Cordova (1998) posit that the cancer treatment lends itself to PTSD symptom development, with aversive treatment and disfiguring surgery. Add to that the threat of loss of life and the social isolation often associated with breast cancer and the risk of PTSD-like symptoms increases (Cordova, et al., 1995).

Not every woman diagnosed with breast cancer will experience PTSD, although Cordova et al., (1995) found that “PTSD-like” symptoms were common in survivors (p. 985). However, there appears to be some correlation among the presence of more advanced stage of disease, younger age at diagnosis, and pre-cancer traumatic experiences with the occurrence of PTSD. Additionally, social support is thought to be a buffer against the development of symptoms (Andrykowski & Cordova, 1998; Cordova, et al., 1995).
Janoff-Bulman’s (1999) model of shattered assumptions closely resembles what happens in a woman diagnosed with breast cancer. According to Janoff-Bulman the key to the process of coping with tragedy is based upon understanding core assumptions about life. Such core assumptions are largely unconscious operating guides that we remain unaware of until an extreme life event happens. These assumptions are our beliefs about the type of world we live in, the justice of the world, and our beliefs about ourselves (Janoff-Bulman, 1999).

Typically, people believe that the world is good, that other people are good, and life will generally be good. Although we know cognitively that there are ugly and bad things that happen, we make the assumption that the world we live in is different, and we expect benevolence. Further, we believe the world is just, and that there will be a logical explanation for good versus bad outcomes in life. Bad people get what they deserve: we blame the victim. We can control what happens to us by right and good behaviors (Janoff-Bulman, 1999; see also Brownell, 1991; Taylor, 1983).

The third assumption is that we believe we are good people deserving of a good life because we do the right things. We will have good outcomes, because we are worthy and because we behave correctly. Janoff-Bulman called this a sense of “relative invulnerability” as a result of “underestimating the likelihood of negative outcomes” (1999, p. 310).

Therefore, when an extreme and traumatic life event happens, our fundamental assumptions are shattered. We are forced to examine our own vulnerability and mortality. The old way of believing is gone; no longer are we secure in what and who we are; and
we now realize that bad things happen, regardless of how good a person is. As a result, denial and emotional numbness surface, similarly to PTSD-like symptoms (Janoff-Bulman, 1999). Breast cancer as a random negative event without apparent causal attribution (Tomich & Helgeson, 2002) occurs in all kinds of people. The woman struck by this disease has her worldview shattered, because she is face to face with being unable to control the randomness of life just by living right.

*Posttraumatic growth and benefit finding*

However, many breast cancer survivors describe the discovery of positive growth and other psychosocial or existential benefits after their intense traumatic experience (Manne, et al., 2004; Taylor, 2000). There seems to be support for the possibility that a greater threat from the traumatic event yields a “greater...opportunity for growth” (Cordova, et al., 2001, p. 176). Examples from survivors of positive findings include a reappraisal of life and its meaning (Sears, et al., 2003), a renewed or increased recognition of the importance of spirituality (Bloom, 2002; Fredette, 1995), reordered goals and priorities (Bellizzi & Blank, 2006; O’Leary & Ickovics, 1995), enhanced sense of purpose, positive self changes, and improved intimacy in relationships (Antoni, et al., 2001; Weiss, 2004), new self knowledge and awareness (Taylor, 2000), improved health behaviors (Manne, et al., 2004), and a new focus on altruism (Nelson, 1996). Supported by Janoff-Bulman’s (1999) model, such attribution of positive meaning to a traumatic experience is indicative of potential healthy adjustment and a search for meaning in the experience (Taylor, 2000).
Calhoun & Tedeschi (2006) identify this positive growth by the widely accepted term posttraumatic growth (PTG), and although it is a fairly recent research interest in breast cancer survivors (Bellizi & Blank, 2006; Cordova, et al., 2001; Sears, et al., 2003; Tomich & Helgeson, 2004; Weiss, 2004), it has previously been investigated in other life-threatening circumstances such as sexual assault, myocardial infarctions, and different adult cancers (Manne, et al., 2004). PTG is also called transformative growth (Taylor, 2000), cognitive adaptation (Taylor, 1983), posttraumatic coping and rebuilding shattered assumptions (Janoff-Bulman, 2004), quantum change (Miller & C’de Baca, 2001), and benefit finding (Tennen & Affleck, 1999). These terms are often used interchangeably in the literature, as they refer to similar and related constructs (Sears, et al., 2003). Such positive growth is conceptualized as the “positive psychological change experienced as a result of” traumatic events (Tedeschi & Calhoun, 2004, p.1). It is more than just coping or returning to one’s previous baseline, and more than simply an intellectual process (Tedeschi & Calhoun, 2004).

Heavily researched, factor analysis supports five domains specific to posttraumatic growth. The first is a changed self perspective, reflective of the upheaval relative to assumptions about the world. A sense of vulnerability and recognition of the world as unpredictable and dangerous are key changes, coupled with the acknowledgement that the person has been tested and survived. A second domain is the recognition of new possibilities, developing new interests or turning towards a new life path (Calhoun & Tedeschi, 2006).
Changes following trauma often include improved relationships and deeper connections with others. Quite often the survivor also develops a greater compassion for others, and Calhoun and Tedeschi (2006) posit that the data support that for many this becomes the basis for acts of service and altruism. Fourth is a changed sense of what truly is important in one’s life. A greater appreciation for intangibles and the preciousness of life are commonly reported as reasons for dramatically altering priorities and goals. The final domain is in the existential or spiritual arena. Calhoun and Tedeschi suggest that in the United States, this often is manifested as religious change, with reports about faith and purpose, while those in more secular nations may focus on the existential nature of life’s purpose and meaning as a result of trauma (Calhoun & Tedeschi, 2006; Pals & McAdams 2004).

Specific to the findings of PTG in breast cancer survivors, the research is still in its infancy (Bellizzi & Blank, 2006). One conflictual finding concerns socioeconomic status. Tomich and Helgeson (2004) found that lower SES was positively correlated with PTG, and they speculated that religious faith, more frequently reported as a method of coping, was a moderating variable. However, others (Cordova, et al., 2001; Bellizzi & Blank, 2006) reported a positive correlation with higher income that afforded greater availability of resources for coping. Other findings are that PTG is fostered by younger age (Sears, et al., 2003), severity of disease (Tomich & Helgeson, 2004), time since diagnosis (Cordova, et al., 2001) and social supports (Weiss, 2004). In fact, Weiss (2004) contended that the woman who has a social context in which she can engage in conversations about her breast cancer and feel emotionally validated has an improved
opportunity for PTG. The interpersonal context would seem to facilitate the cognitive processing essential to PTG. This finding would be highly significant to survivors, especially in view of the likelihood of social isolation that seems to occur in the case of breast cancer survivors (Weiss, 2004).

Conversely, not all survivors report positive changes after their breast cancer experience. There is some question whether or not PTG is truly reflective of actual change, or if it is merely an illusion fostered by the individual’s attempt to cope (Stanton & Low, 2004). It could reflect a type of embellished improvement at the expense of denigrating what they formerly were really like, in order to give the impression of growth and to feel better about themselves (Park, 2004; Tomich & Helgeson, 2004). Or does the survivor perceive that it is more socially desirable to report positive outcomes from the cancer? It appears that culturally we in the United States are socialized to expect to hear stories of positive personal growth after the experience of crisis or trauma (Pals & McAdams, 2004). “The prison of positive thinking” is referred to by cancer survivors who claim that they are exhorted to keep a positive attitude and look for the good (Cordova, et al., 2001, p. 182). Tomich & Helgeson (2004) contended that it is highly likely that there are both positive and negative changes in the lives of cancer survivors, and that clinicians need to avoid placing expectations for benefit finding or positive meaning-making on the clients.

Calhoun and Tedeschi (2006) maintained that trauma disrupts the individual’s assumptive world (see also Janoff-Bulman, 1999) which disorganizes the “personal narrative” of the individual and divides the person’s life into before and after (p. 9) (see
also Miller, 2004; Miller & C’d de Baca, 2001). Cognitively, the traumatized person now has to incorporate the negative event into a new life narrative. Initially, this cognitive process may take the form of intrusive automatic thoughts, which later are under more conscious control in a form of rumination. Rumination, as defined by Calhoun and Tedeschi, is a deliberate and repetitive type of thinking that reminisces about the event, attempts to make meaning about what happened, and begins the work of rebuilding and restoring assumptions about the world (2006). With comprehension, understanding, and time comes coping and ultimately meaningfulness, or “meaning reconstruction” according to Neimeyer (2006, p. 69).

Meaning Making

It is part of the human experience to attempt to understand why certain things happen. When there is a loss, the individual grapples with doubts and questions (why? and why me?), and searches for the significance of the experience. As described earlier, there is often a shattering of world assumptions (Janoff-Bulman, 2004) and possibly a pervasive disorganization of one’s emotional well-being as a result of loss and trauma (Calhoun & Tedeschi, 2006; Neimeyer, 2001a, 2001b, 2004). Part of the struggle is an attempt to understand and to derive meaning from what has happened (Calhoun, et al., 2000; Collett, 1998; Neimeyer, 2006), since we are meaning making beings.

Basing their work on Park and Folkman’s (1997) model of coping, both Collie and Long (2005) and Schoen and Nicholas (2004) studied the construct of global versus situational meaning as an aspect of coping used by women with breast cancer. They defined global meaning as that fundamental assumptive expectation about the
meaningfulness of life, similar to an existential meaning, while situational meaning is that ascribed to the person-environment intersection of a particular event; i.e., breast cancer. Global meaning reflected the necessity for order and purpose in life, the belief that life “makes sense” (Collie & Long, 2005, p. 844), and the attempt to place the experience within the context of the total life pattern. Purpose is that quality of transcendence, of going beyond oneself with the added value to life in relation to others. Their conclusion was that suffering was bearable if it had meaning; therefore, an important task might be to help the individual attempt to make meaning of her suffering during her cancer experience (Collie & Long, 2005).

The subjective significance of an illness is related to situational meaning. An individual might view her cancer as a challenge, as punishment or weakness, as irreparable damage, or as an experience of value. The value added positive attributions of meaning include benefit finding (Tennen & Affleck, 1999), improved quality of life (Schoen & Nicholas, 2004), enhanced positive meaning from having successfully lived through a traumatic event (Pelusi, 1997), and meaning reconstruction in posttraumatic growth (Neimeyer, 2004, 2006). Moch (1995) who has researched breast cancer since 1987, found support for the idea that enhanced inner awareness, personal growth, and discovery of a new life after facing death are part of the paradoxical positive meaning making in survivors.

Reflecting upon a traumatic event or a serious illness can yield a deeper meaning for the individual in a personal, as well as a professional, realm. Schwind, a nurse educator, used personal illness as a springboard to research the meaning making process
of illness, and described the importance of the emotional power of storying and the shaping of one’s life by reflection on personal experience (Schwind, 2003; see also Connelly & Clandinin, 1986; Clandinin & Connelly, 2000).

A social constructionist perspective is that meaning is constructed in the relational aspect of interpersonal interaction. Therefore, it is posited that survivors reconstruct their life stories via the breast cancer experience, especially within the social context of telling their stories to others. As counselors we have the opportunity to be that “empathic witness” mentioned in Collie & Long (2005, p. 847), present and listening, facilitating the construction of a new life narrative that encompasses the woman’s breast cancer experience. The current research will therefore consider the process of *storying* through the use of personal narratives about the lived experiences of breast cancer survivors.

*Narrative Process*

As part of the budding literature base on posttraumatic growth, Niemeyer (2004, 2006) took the position that the person undergoing a traumatic experience uses the medium of storytelling to make meaning of the trauma. Neimeyer’s stance was that identity and sense of self are socially constructed via interpersonal interaction. Stories the individual tells about herself or himself, as well as stories others tell about the individual, become part of the self narrative. The life story is not only a basis for identity, but possibly the “fundamental frame that holds the entire puzzle together” (Pals & McAdams, 2004, p. 65). Riessman (1993) contended that personal stories in actuality fashion the individual’s identity. Exposure to severe negative events disrupts that person’s identity and sense of self, invalidating the core assumptive values, interrupting
the personal story, and destroying the meaning of one’s world (Janoff-Bulman, 1999; Little, et al., 2002; Neimeyer, 2004, 2006).

Learned as children, the telling of stories organizes experiences around time dimensions (past, present, future), ideal and real selves, and interpretations of events, in an attempt to “translate knowing into telling” (White, 1989, p. 1, as cited in Riessman, 1993, p. 3). Placing events in some methodical order and selecting what details to include and what to exclude are aspects of the individual’s agency in constructing a new narrative with a new coherence (Josselson, 1995; Niemeyer, 2004). Storying includes the fundamental structure of a beginning, middle, and an end, and may be “the basic schematic structure for much of human thought” (Niemeyer, 2004, p. 53). Anthropologist Bateson maintained that a narrative style is how we learn, and that we “think in metaphors” and learn “through stories” (Bateson, 1994, p. 11, as cited in Clandinin & Connelly, 2000, p. 8). Narratives are our attempt at making sense of our experiences and at communicating the meaning of such happenings (Chase, 1995).

Through the story, the breast cancer survivor can relate her experience, and this may become a fundamental growth process for her. The story can actually become the agent for change, as she retells and reconstructs the illness experience (Schwind, 2003). As Clandinin and Connelly claim, we “live stories, and in the telling of them reaffirm them, modify them, and create new ones” (1994, p. 415, see also Schwind, 2003). Ideally, the survivor’s new stories will reflect healing, growth, and positive change.

Trauma often precipitates an initial reaction of silence, an unwillingness to even consciously consider what has happened, let alone talk about it. However, designing a
story about an event can be an avenue to making sense of it (Collett, 1998; Neimeyer, 2004, 2006; Riessman, 1993) and to learning from it as one reflects and seeks the meaning of it (Schwind, 2003). As the traumatized person tells the story about the event, or really about life and living in its memory, the past history becomes part of the present reality in the telling and the interpretation, and foreshadows the as yet unknown future (Josselson, 1995). Ultimately, the interpretation can lead to new stories in the process of living, telling, retelling, and reliving (Connelly & Clandinin, 2006).

Narrative inquiry is the methodology for investigating the interpretation of human experience as it is described in the storied lives of individuals grappling with making sense of life events (Chase, 2003; Clandinin & Connelly, 2000; Connelly & Clandinin, 2006; Josselson & Lieblich, 1995). It is discussed in detail in Chapter III on research methodology. The underlying philosophy of the current research is that the experiences of breast cancer survivors are important stories needing telling. These stories link the knowledge of the journey with the survivors’ personal self identities. At the same time, they communicate meaning of the illness, and provide a portal through which the clinician might learn the significance of breast cancer to the survivor. The opportunity of being able to answer the questions of “so what?” and “then what happened?” (Riessman, 1993) assisted survivors to restory their life narratives. Additionally, clinicians are more likely equipped to plan for appropriate therapeutic interventions with the woman who has breast cancer.
Chapter II Summary

The primary purpose of the literature review was to identify and discuss the existing studies about change, about breast cancer, and about meaning making during the survivors’ lived experience of breast cancer. The first section considered a conceptual overview of change from the theoretical basis of chaos theory and quantum change theory. The second section discussed the survivorship experience from the standpoint of chronic illness, posttraumatic stress, and the potential for positive change in posttraumatic growth or transformative change. Finally, an initial explanation of meaning making in the life of the survivor through the use of narrative was presented to establish the framework for the specific research methodology used in this study: the phenomenological approach to the breast cancer experience via individual case studies and cross case analysis through the use of narrative analytic methods.
CHAPTER III
METHODS

Introduction

“We had the experience, but missed the meaning.” T.S. Eliot

The traditional paradigm for scientific inquiry has been a quantitative methodology with its emphasis on measurement, causation, and relationships between variables. Definition of the problem, explanation, prediction, and descriptive or inferential statistical analyses are utilized to examine numerous hypotheses about the phenomenon of interest. Experimental designs employing surveys, questionnaires, or instrumentation elicit numeric data which are then analyzed to test or verify existing, previously stated theories. Concerns about reliability and validity are central during the design, the data collection, and the analysis of the research (Morrow & Smith, 2000; Pedhazur & Schmelkin, 1991).

It is interesting to note that Freud, and later Piaget, used case studies, a qualitative methodology, in the development of their respective psychoanalytic and cognitive developmental theories. Although such early foundations came from a qualitative nature, the historical tendency in the disciplines of psychology, and later on counseling, has been to emulate the focus of the hard sciences on objective data, linear causality, and probability, perhaps in an attempt to seek validity as a true science (Merchant, 1997).
However, in the past ten years, qualitative methodology is increasing in counseling research, and more articles published in professional journals utilize qualitative methods (Berrios & Lucca, 2006).

In the early 1900s, qualitative methods were used by anthropologists in ethnographic studies of other cultures via fieldwork observations. Post World War II, the changing social climate lent itself to research focused on the underdog, with deviance and social control becoming important topics for study. The classroom also became a research field. Rogers was able to bridge education and psychology and strongly influenced the classroom teachers of the day with ideas for non-positivist educational reform (Tesch, 1990). Studies on the Vietnam War and the Civil Rights movement lent momentum to the infusion of political philosophies into the study of self and society as well as the language of discourse for teaching and learning (Denzin & Lincoln, 1998; Tesch, 1990).

According to Denzin and Lincoln (1998), by the 1970s and 1980s qualitative research had gained many followers and spawned many approaches. The lines “between the social sciences and the humanities had become blurred” (p. 18) as issues of gender, class, and race became significant. No longer limited to education and anthropology, qualitative research has surfaced in other disciplines such as counseling, nursing, family therapy, medicine, and social work (Merchant, 1997). Its popularity today may reflect a growing disenchantment with the traditional research worldview of logical empiricism and positivism emphasizing measurement, prediction, and control, and a burgeoning interest in a contextual approach that includes description and discovery of meaning (Osborne, 1994).
The subsequent sections of this chapter address a basic overview of the philosophical foundation of qualitative research with attention to the epistemological and constructivist position of this stance and support for the selection of this particular mode of inquiry. Background information will consider the philosophical underpinning of phenomenological research that utilizes a case study approach with narrative analysis. An overview of narrative methods, coding procedures, and analytic methods will be included. Additionally, there will be a discussion of the ethical process for the protection of the rights of the human subjects who participated in this study, including procedures for recruitment and the interview questions asked of each participant.

Qualitative Research

Qualitative research is a method of inquiry that differs philosophically from quantitative research primarily on the assumptions of what constitutes reality and how it is best measured. A qualitative philosophy is a naturalistic, individualized approach that assumes a socially constructed rather than an objective factual reality, searches for understanding instead of causality, and is conducted by a researcher immersed in the setting as an instrument of the research and in relation to the participants, not one who is detached and focused on data collection (Newman & Benz, 1998; Rew, Bechtel, & Sapp, 1993). The underlying objective of qualitative research is to understand the participant meaning, that meaning given to the life experience or the phenomenon of interest from the perspective of the participant (Merriam, 1998).

Data are nonnumeric, verbal, and visual in qualitative studies and obtained by field methods such as observations or interviews. Able to respond, adapt, and attend to nonverbal behaviors, the researcher is an active participant and becomes the primary
instrument of the research, the mediator of the data as a “vessel or vehicle through which the participant makes known an intricate story of a ‘slice’ of the participant’s life” (Rew, et al., 1993, p.300). The qualitative researcher recognizes that a single interview “slices into a person’s life at a certain point…and may not necessarily apply to another point in time” (Shapiro, Angus, & Davis, 1997, p. 551). Qualitative research is context-bound and attempts to understand the participants within their specific social context, not necessarily to generalize the findings to other survivors (Raveis & Pretter, 2005). The researcher physically goes to the participants to interview or observe them, rather than being an objective bystander using an inanimate psychometric test. The knowledge claims are idiographic and view individual participants as the unit of study, rather than nomothetic in nature and directed towards large sample groups (Merriam, 1998; Morrow & Smith, 2000).

The researcher is interested in the experience of the person as he or she relates with the environment, self, and others. Clandinin and Connelly (1994) state that social science research is based on “the study of experience” (p. 414) and experience is expressed in the stories people live and tell. The life stories provide the basis for inferences and interpretations by the researcher, and the empathic stance of the researcher allows for unexpected findings to surface which can add to the richness of the study (Merriam, 1998; Morrow & Smith, 2000).

Epistemology

Epistemology can be defined as how a person knows what he or she knows. This knowing would include how one would inquire about the world, whether that person would look objectively or subjectively at situations or experiences, what might be
considered important to know, and how one defines reality (Patton, 2002). Creswell (2003) proposes that researchers consider three elements vital to the type of research intended: the philosophic assumption of what knowledge is; the general strategies of inquiry planned; and the specific detailed methods of data collection, analysis, and reporting. For the qualitative researcher, epistemology, or how one knows, is based on the assumption of social constructivism in which knowledge is constructed, and the individual seeks to understand the world through the meaning of life experience (Clandinin & Connelly, 1994; Creswell, 2003). Qualitative research, accordingly, is a method of inquiry that “focuses on meaning in context” and the process of “understanding from the perspectives of those being studied” (Merriam, 1998, p. 1).

Further, as an individual interacts with her or his world, the social context influences the subjective meaning of the experience. Experience, truth, and knowledge are relative, socially constructed, uniquely interpreted and shaped by the individual, as opposed to being identified and evaluated by the scientific method, a postpositivist assumption utilized in quantitative research. The social, historical, political, and cultural context is important to the interpretation (Creswell, 2003; Merchant, 1997). According to the tradition of hermeneutics, a literary critique method for biblical textual analysis now used in the social sciences, interpreting and understanding the person’s experience are based on the language, actions, and context of that individual’s everyday life (Morrow & Smith, 2000).
Strategies of Inquiry

Creswell (2003) described strategies of inquiry as the next step, providing specific procedural directives for research design. Typically, qualitative studies will have designs that are flexible and emergent to changing conditions that develop during the process (Merriam, 1998). Some examples include grounded theory, narratives, case studies, ethnographies, and phenomenologies. Phenomenological, case studies, and narrative inquiry will be discussed as the strategies to be used in the present research.

Phenomenological research

Phenomenological research focuses primarily on an individual’s subjective understanding of everyday life and how he or she has interpreted the actions of self or others as meaningful (Schwandt, 2000). Creswell claimed that phenomenological research is not only a strategy of inquiry, but also a school of philosophy, due to the process of attempting to understand the “lived experiences” and the “essence” of human experiences (phenomena) described in the research (Creswell, 2003, p. 15; see also Merriam, 1998). Essence refers to the core meaning that is mutually understood about common experiences (Merriam, 1998). Phenomenology is almost an intuitive process, a means of “exploring lived-experience…from the inside rather than from the natural science perspective of observation and measurement” (Osborne, 1994, p.171).

Phenomena are typically reported by the participants through spoken or written accounts of their subjective conscious experience in agreement with the importance of language as a primary means of making sense of one’s world (Merchant, 1997).

The principal focus of the individual’s experience of a specific phenomenon is more important than whether or not it is generalizable to others, a question of external
validity in quantitative research (Newman & Benz, 1998; Osborne, 1994). Although there is some value in the desire to generalize research findings to wider groups of people, and some pressure from the academy to do so, the qualitative researcher finds value, not in probabilities, but in the specific circumstances of the individual (Denzin & Lincoln, 1998). In fact, Chase claimed that narrative researchers “reject the idea” that their narratives must represent larger populations (Chase, 2005, p. 667).

Riessman (1993) addressed such concerns about qualitative research through the concepts of plausibility and coherence. The underlying assumption is that an individual’s account of the experience is told from the point of view of the narrator, and the resulting interpretation by the narrator and the researcher is a socially constructed interpretation. The focus of plausibility becomes trustworthiness, not reliability, and not the objective truth. The key question is whether or not the interpretation is convincing and makes sense. The researcher adds to plausibility of the findings by including verbatim accounts in transcripts, by considering alternative explanations for the conclusions, and in verification of the accounts with the participants. Known as member checking, the subject of the research is provided with the opportunity to verify and concur with the narrative that is recounted, which strengthens the plausibility of the research by increasing its trustworthiness (Riessman, 1993).

A second factor is the criterion of coherence. Global coherence refers to that overall goal of the participant in telling the story; for example, to justify a particular choice or action. Local coherence includes the use of linguistic and stylistic devices in telling the story; such as how the events are temporally arranged, where is the emphasis, and how are contrasts articulated to make a point. Thematic coherence is especially
important. What is the content of the narrative, and are there repeating themes within one and across several cases? Riessman posited that in a narrative in which all three forms of coherence are evident, the researcher’s interpretation of the material is strengthened, and one can “learn about the general from the particular” (Riessman, 1993, p.70).

Carter, an early researcher who conducted one of the foundational research studies on the lived experiences of breast cancer survivors by using phenomenological methods, agreed that the difficulty in generalization is an inherent limitation to qualitative methodology. However, in qualitative research, “the experience of the individual is the unit of analysis…the complexity, diversity, and uniqueness of individual experience is the focal point” of the research (Carter, 1989, p. 323).

Case study approach

To learn about lived experience it is necessary to obtain reports from individuals who have experienced the phenomenon, and one strategy would be the use of a case study approach. Case studies are restricted to a specific time and activity, and Merriam considers that the “bounded system” of the object of the study is the defining aspect constituting a true case study: an “entity, a unit around which there are boundaries” (Merriam, 1998, p.27).

A case study uniquely contributes to understanding phenomena through an in depth investigation of such an event in a real-life context (Bullough, 1998; Creswell, 2003). It provides rich description, it is particularistic about a specific focus, and it is heuristic in its ability to enhance the understanding and knowledge of the researcher or reader (Merriam, 1998). According to Yin (1994), a case study is the preferred research strategy for examining a how or why question about contemporary, not historical, events.
beyond the control of the researcher. Typically, the focus is on the process instead of the outcome, and discovery is valued over confirmation of a hypothesis. Case studies additionally have advantages when contextual conditions are important to the study of the phenomenon and when there are multiple sources of information and data. Case studies may, but are not required to, include direct observation, and the primary unit of analysis is the single person, program, event, or entity (Merriam, 1998; Yin, 1994).

Narrative inquiry

Narratives are the stories tellers tell; a story with a beginning, middle, and an end that means something to the teller and has a point (Bell, 1999). Narrative is fairly new as a strategy of inquiry for research, “a field in the making” (Chase, 2005, p.651), although it has historical roots in the humanities. Story telling was part of the early history of psychology as evidenced in the narrative about religious history complied by James (1902, as cited in Bakan, 1996, and in Miller, 2004).

As a strategy of inquiry (narrative can also refer to a method of analysis or a type of psychotherapy), it is asking the participant to tell a story about her or his lived experience and how that individual begins to make sense of life’s events, a type of conversation with the self. It is not a mere reporting of the facts, but a meaning-making attempt to organize a coherent whole out of many experiences and to communicate that meaning (Chase, 1995; Josselson, 1995; Smyth & Pennebaker, 1999).

The understanding of narrative is that people shape their lives on the basis of stories about who they are in relation to others, and they understand their past through interpreting these stories. As young children, healthy development is within the interconnections of relationships with the parents. As the child grows, his or her self
continues to develop throughout the changing contexts of the family relationships and through the narratives told by parents and other significant people. When people tell stories about their experiences, they actually create themselves in the way they prefer others to know them (Ivey, Ivey, Myers, & Sweeney, 2005; Riessman, 1993).

Individuals tell stories that are representations of their experiences and certain events are more meaningful than others. They choose what to include and what language to use in the telling. The primary focus of narrative inquiry is to “give voice to the subject: to collect, interpret, and present materials about human experiences that preserve this voice of the subject” (Bell, 1991, p.245).

Narrative facilitates making world and life experience personally meaningful (Collett, 1998). Chase defined narrative inquiry as “an amalgam of interdisciplinary analytic lenses, diverse disciplinary approaches, and both traditional and innovative methods—all revolving around an interest in biographical particulars as narrated by the one who lives them” (Chase, 2005, p.651). Consequently, narrative inquiry is the study of the story about the experience (Connelly & Clandinin, 2006). Using narrative as an inquiry, the researcher invites the participants to tell stories about their life and their experience with a focus on stories of deep importance and significance (Chase, 1995). Josselson (1995) posited the only way to understand people is to investigate the human meaning of their experiences. Chase (1995) reminded researchers to craft interviews that invite stories, rather than elicit facts and information, and demonstrated the interactional nature of narrative inquiry in research about women superintendents of public schools (Chase & Bell, 1994).
Connelly and Clandinin suggested three “commonplaces of narrative inquiry” that simultaneously need to be addressed (Connelly & Clandinin, 2006, p. 479). The first is that events have temporality, a past, present, and future, and are in a constant state of transition. The second is the importance of social context. What are the personal conditions of feelings, hopes, and desires and the social existential conditions such as the environment, other people, and other associated factors? This commonplace also would include the relationship between the participant and the researcher. Connelly and Clandinin (2006) maintained that the inquirer or researcher is always in relationship with the participants, and therefore, it is essential that the researcher in narrative inquiry not bracket herself or himself out of the research, as is acceptable practice in other strategies of qualitative inquiry.

The third aspect is place, the location of the specific physical space where the events occurred and where the inquiry occurs. For example, breast cancer treatment occurs in many different locations, such as hospitals, clinics, outpatient centers, or radiation departments, and recovery may occur at home, survivors may be back to work, and additionally, personal interviews may occur in various locations. All of these need to be considered under the commonplace of place. Connelly and Clandinin (2006) urged that all three—time, context, and place—be considered in terms of actual interview questions asked.

In terms of the lenses through which the inquiry is viewed, Chase (2005) posited five lenses for consideration. One distinction of narrative is that it is retrospective with meaning shaped and ordered from past experiences. The narrative includes point of view, emotions, chronology, and unique aspects of actions and events according to the narrator.
Another lens is the consideration of narrative as verbal action. Story tellers are actors and performers, actively creating the what, how, and where of the story. Additionally, narratives are particular to the individual, but the inquirer attempts to look for similarities and differences across narratives of other participants.

A fourth lens considers that this particular story is told in this particular setting for this particular audience for the teller’s particular purposes. This reflects the concept of the story as socially constructed and shaped between the participant and the inquirer. Lastly, the narrative itself is further shaped and narrated by the researcher during interpretation, writing, and presenting or publishing the stories. Narrative inquirers become narrators themselves as they develop meaning and order out of what they have studied and then use their own voices to convey the information to their particular audiences (Bell, 1999; Chase, 2005; Reissman, 1993).

Qualitative Research Methods

After identifying the epistemological assumptions and the strategies of inquiry, the next step is to plan for the specific methods of data collection and analysis (Creswell, 2003). For the qualitative investigation of the current study, the primary data collection method was the semi-structured in-depth interview conducted by the researcher (see the following sections) in a location of the participant’s choosing. Additionally, the use of the researcher as an instrument and the researcher’s journal are part of the data collection methodology (Maykut & Morehouse, 1994). The primary intent was to listen for emerging themes about the survivorship experience. Although thematic coherence in the content of the stories was evident (Reissman, 1993), an important observation was looking for stories that disconfirmed what appeared to be any dominant theme (Guba &
Lincoln, 1989 as cited in Miller & Crabtree, 2000). The data further expanded the knowledge base for counselors who might work with survivors of breast cancer.

*Self as instrument*

In qualitative research, it is commonly accepted that the researcher will be the instrument of both data collection and interpretation (Maykut & Morehouse, 1994; Patton, 2002; Rew, et al., 1993). The traditional quantitative paradigm has been that the researcher remains objective, distant, and value-neutral. In a true experiment, embedding instrumentation into the study alters the data. Consequently, the idea of an active participatory researcher in qualitative methodology may raise concerns. However, based on teachings of Guba and Lincoln, respected qualitative researchers, qualitative research is “inevitably entwined with the perceptual frames, histories, and values of the inquirer…is unabashedly subjective, unapologetically imbued with the individual perspectives and frames of the inquirer” (Greene, 1998, p. 390).

The qualitative inquirer is described as a *bricoleur*, a term from anthropologist Lévi-Strauss to describe one who is able to creatively take differing materials, for example information, and put them together in novel ways, similar to piecing together a quilt from different fabrics or making a film from various images. Denzin & Lincoln, (2005) applied this definition to the emergent quality of qualitative research in that the researcher (*bricoleur*) is self-reflective, able to adjust and adapt to the person and the context, and able to go with the story the participant brings. Themes from the literature base (for example, positive growth following trauma, fears of cancer recurrence, and developing a survivor identity) were confirmed, expanded, or even contradicted by the
analysis of the data. The research described new understandings and themes that emerged from the data about the survivorship trajectory.

Qualitative research depends upon the relational aspect between inquirer and participants. Personal attributes of the researcher have the potential to enhance the process of the interaction between the participants and the researcher. Rew and colleagues (1993) identified some essential characteristics and behaviors for the qualitative inquirer: asking unambiguous questions, treating people with unconditional positive regard, being authentic, openness to learning from the participants and willingness to accept feedback, and fostering an egalitarian and reciprocal relationship while being aware of the potential for power differentials. People are complex and unpredictable. The researcher as instrument has the ability to flexibly observe and attempt to understand the lived experience of the participants and the meaning they attach to that experience while seeking for clarification in the immediacy of the interview (Maykut & Morehouse, 1994; Rew, et al., 1993). The questions and the interactions must be designed with these crucial goals in mind.

However, it is inevitable that the researcher is subjectively involved in the process and needs to be able to bridge the conventional distance considered appropriate for researcher and participant (Morrow & Smith, 2000). It is a realistic concern that the researcher could become too personally involved with the participants. Patton (2002) suggests the researcher develop the stance of “empathic neutrality” (p. 50), a type of emotional middle ground. Becoming too closely involved may cloud the inquirer’s judgment about the narratives, and yet remaining too distant may reduce understanding and relational space.
Trustworthiness

As in any research endeavor, there must be safeguards in the design to increase the trustworthiness of the inquiry and the accuracy of the findings. Although objective reality is never completely captured, the goal is to present an in-depth interpretation of the phenomenon under study (Denzin & Lincoln, 1998). The researcher must attempt to portray the participants’ experience as accurately as possible, fairly approach the participants and the information generated, and support the authenticity of their experiences (Cihlar, 2004).

As an “ethical stance” of the researcher (Cihlar, 2004, p. 54), I utilized several strategies to enhance the trustworthiness of the current study. Initially, I identified my own presuppositions about the phenomenon of breast cancer survivorship in order to be alert to what are my experiences, my meanings, my understandings, and what belongs to the participant: a process called “bracketing” (Janesick, 2000; Tesch, 1990). My plan was to seek rich description of the phenomena involved by holding two interviews with each participant to increase the trustworthiness of the data. I utilized member checking during and after the interviews to verify accuracy, and I sought not only confirming data, but also discrepant data in the interviews. I kept audit trails and a researcher journal, a written record of all my activities, from the interviews, the transcripts, my reflections, and any analytic measures, so that another researcher might follow my “trail” to understand and evaluate my work (Maykut & Morehouse, 1994). I also had a colleague read the transcriptions so that I had my own member checking about the conclusions I drew.

The verbal recordings and printed transcripts assisted me in deriving a more objective interpretation. Finding the specific key words and phrases from the narratives,
interpreting them as would an informed reader, checking back with the interviewee as to the accuracy of the interpretation are all steps that promoted bracketing. Also using comparative analyses of statements or behaviors confirmed or illustrated content that did not fit (Janesick, 2000).

Janesick (2000) promoted the concept of crystallization in lieu of triangulation (the use of multiple investigators, research methods, or data sources) (Creswell, 2003; Denzin & Lincoln, 1998; Merriam, 1998) in the qualitative process. The current research was informed by various disciplines, including education, counseling, nursing, and medicine: one aspect of crystallization. Investigator triangulation, another type, was used in working with a colleague who also reviewed the transcripts and discussed generation of themes and data. Listening for more than one instance of a phenomena and seeking different meanings and perspectives are supported by theoretical triangulation (Janesick, 2000; see also Cihlar, 2004).

*Researcher Stance*

Therefore, the credibility and the rigor of the research depend to a great extent on the personal integrity, skill, competence, and life experience of the researcher (Patton, 2002; Rew, et al., 1993). It is important to reveal appropriate information about the researcher’s personal and professional attributes, so as to allow for any possible effects on the “data collection, analysis, or interpretation” (Patton, 2002, p. 566) and to indicate the researcher’s position as an insider or outsider to the phenomenon of interest (Morrow & Smith, 2000).

I have previously indicated my position in Chapter I in the Researcher Stance section, but I briefly summarize it again. I am a Registered Nurse who has cared for
breast cancer patients. I am a Professional Counselor who has undergone a paradigm shift away from a prescriptive medical model to a holistic, individual agency model. I am the daughter-in-law of a breast cancer survivor, and I had a very good friend die of breast cancer. I am additionally an insider (Morrow & Smith, 2000) to the breast cancer population, since I was diagnosed with and treated for breast cancer myself. I empathically understand the need to tell my story about this disease, and to have a collaborative relationship with my treatment providers. I have experienced the shattering of my assumptions about the lack of safety in life, as well as the positive growth and benefit finding as a result of working through my journey. I believe that with the overwhelming increase in the incidence of breast cancer and the potential for negative emotional states in the survivor, that the counseling practitioner needs to hear the stories of the lived experience of individuals who battle breast cancer. And I hope for the development of treatment models that promote a more empathic, growth-oriented therapeutic environment for the survivor.

Accessing Participants

Qualitative research typically utilizes a small sample or even a single case for analysis (Patton, 2002). The goal of the qualitative inquiry is to gain a deeper understanding of a particular phenomenon experienced by a specific group of people. The sample selected is not random, as in the quantitative inquiry, but purposeful: it may include information rich cases to further increase the depth of the study, it may include cases of extreme or typical status depending on the bounds of the study, or it may be from a homogeneous group (Maykut & Morehouse, 1994; Patton, 2002). A recommended type of sample is the maximum variation sample (Patton, 2002) which strives to access the
most likely heterogeneous group of people that experience the phenomenon. The strength 
of maximum variation is that any common themes that develop across the sample will be 
of greater interest and credibility as a result of the greater variance in people. The results 
of such sampling will be detailed rich descriptions of individual case experiences, plus 
the potential for important common patterns across the cases (Patton, 2002). Hence, the 
current research utilized a small, purposeful sample of maximum variability, survivors 
that differed in age, ethnicity, race, and socioeconomic status. It was proposed that six 
participants would allow for a substantive understanding of the essence of the 
experiences (Morse, 1994, as cited in Ryan & Bernard, 2000). However, it happened that 
an additional two participants were added to provide more variability in age, ethnicity, 
geography, and class.

It was also planned that participants were selected on the basis of convenience 
and opportunistic emergent sampling. Referrals were provided by local physicians, who 
had flyers describing the research and the researcher (Appendix C). The sample was not 
random, as there was some selection bias on the part of the physicians, but this is not a 
concern for a qualitative model. Additionally, other participants were referred by 
individuals who knew that they had been treated for breast cancer, and one survivor was 
known by the researcher.

Selection of Participants

For the purposes of the current research, participants had to meet certain criteria. 
They had to be women who had been diagnosed and treated for breast cancer. While 
breast cancer is not a disease limited to women (ACS, 2006), it is considered a woman’s
disease by conventional wisdom. Additionally, as researcher, my interest and clinical experience has been primarily in the realm of women’s issues.

Participants were survivors who had completed the initial treatment phase of diagnosis, surgery, chemotherapy, and/or radiation for the purpose of this study. There has already been a large body of research and clinical information about the early treatment stages (Carter, 1989; Ganz, et al., 2004; Tomich & Helgeson, 2002) and much more needs to be learned about the process of survivorship over the long-term.

Continuing treatment itself constitutes a complex stressor over time, which may delay some of the transformative changes (Andrykowski & Cordova, 1998). Moreover, the posttraumatic growth literature supports that some degree of coping to the trauma must take place before the occurrence of the necessary cognitive processing for PTG, and that there is a time lag between the event and such ruminatory processes that enable the individual to appreciate the irrevocable change and derive meaning from it (Bellizzi & Blank, 2006; Calhoun & Tedeschi, 2006).

In addition, participants were selected before reaching the five year anniversary mark. Bellizzi & Blank (2006) posited that loss of clarity about attitudes and situations in the cancer experience is possible after an extended period of time post treatment, and they suggest an outer limit of four years. Studies have been inconsistent in findings about the timing of growth, partly because differing time periods have been used (Tomich & Helgeson, 2004). Much of the data has been collected “far after the experience” with the expectation that growth requires an extended period for working through what has happened (Manne, et al., 2004, p. 442). Sears and colleagues found significant positive growth at twelve months post diagnosis, claiming a longer time was predictive of more
growth, and yet they cautioned against increased danger of recall bias the farther away the assessment is from the experience (Sears, et al., 2003).

It is also likely that survivors will make positive changes immediately or shortly after a traumatic event (Manne, et al., 2004). Weiss (2004) stated that survivors closer to the time of diagnosis reported higher levels of PTG than those who were more distant. Therefore, to help minimize the risk of recall bias, and to avoid losing the emotional intensity and clarity of recollection, this study utilized participants who had not passed the five year anniversary date. Although the medical community no longer endorses the five year mark as a cure, there is still much emotional valence on the part of many survivors to view that as meaning they are cured (Tomich & Helgeson, 2002), and it is possible that that benchmark might alter a survivor’s perspective on how she experienced her earlier state.

*Interviewing*

Simply described, interviewing is asking questions and receiving answers. Interviews are likened to conversation, which in the original Latin means “wandering together with” (Warren, 2002, p. 86), with one person asking and listening and the other responding. Although a social endeavor, the purpose of a qualitative interview is not a social event, nor a dialogue between two friends. For research purposes, interviewing is a common method for data gathering and a recognized source of information. In the constructivist manner of qualitative interviewing, the purpose is a guided conversation to listen for meanings and derive interpretations, more so than to extract information (Fontana & Frey, 2005; Warren, 2002).
Although there is some strong support for a qualitative interview that is open-ended and non-structured to allow for total flexibility to go where the participant leads, especially for the experienced researcher (Riessman, 1993), the present study utilized interview questions that are structured and based in the literature discussed previously (Fontana & Frey, 2005; Merchant, 1997; Warren, 2002) (See the proposed interview guide in Appendix F). The interview guide moves from broad exploratory opening questions that guide the discussion to questions that are more thematic or deductive, with supplemental probes as necessary to co-construct meaning (Reissman, 1993). Questions were applied flexibly to the specific participant, while the researcher attended and listened actively, probed for further clarification, and varied the direction as appropriate (Fontana & Frey, 2005; Merchant, 1997; Morrow & Smith, 2000; Warren, 2002). Warren (2002) suggested that this approach provides rigor and allows for sound practice in conducting the interviews, while still promoting researcher flexibility to remain alert for relevant emerging meanings within the stories.

Narrative Analysis Overview

Narrative analysis is the means by which the researcher attempts to answer the question “why was the story told that way?” (Riessman, 1993, p. 2). The object of the research becomes the story itself (Riessman, 1993). Part of the analysis of the stories, therefore, is to consider how the story is ordered by the narrator in the process of making sense of the experience (Riessman, 1993, 2002). When the researcher listens to the participant describing her experiences, it is an acknowledgment that the survivor has a voice, has something to say (Clandinin & Connelly, 1994), and is an active agent of her own knowing (Chase & Bell, 1994).
Both Bell (1988, 1999), who investigated experiences with cancer in DES (diethylstilbestrol: a drug prescribed to mothers to prevent miscarriages) daughters, and Riessman (1993, 2002), whose work has focused on situations of life disruptions, such as divorce, abuse, and chronic illness, have followed a format of case-centered study of personal narratives. They provided explicit transcripted material from the interviews that supported the finding that people tell stories which have sequence and order while allowing the messiness of life experiences to evolve into an organized plot that makes a point (Bell, 1988, 1999; Chase, 1995; Riessman, 1993, 2002). Typically, past experience is considered in view of present life with the narrator selecting events that make the story coherent, in a sense “liv[ing] life forwards but understand[ing] it backwards” (Josselson, 1995, p.35). How the narrator interprets that experience is an important aspect of the story, with the individual’s time, context, and perspective lending agency and subjectivity (Riessman, 1993).

Linking structure and content to knowledge production helps the researcher understand how people create meaning and construct their personal identities from their stories (Bell, 1999). Attending to the structure and form is an important aspect of Bell’s analyses of the narratives of DES daughters, as well as an example of the researcher’s role in the joint construction of the narratives in the interview settings (Bell, 1999). Bell and Riessman both included false starts, repetitions, pauses, and nonlexical devices in the transcribed interviews, based on the belief that narratives are more than just content and that how someone tells about events is a clue to the meaning of the events (Bell, 1999; Riessman, 1993).
One model of the narrative analysis process is Riessman’s (1993), in which the first level is attending, or making a choice about which phenomena are meaningful. This would be enacted on the part of the narrator, deciding what to include in the story, and on the part of the researcher, determining what is the focus of the inquiry. The next level is telling about the phenomenon from an insider’s position. The teller interprets and interactively tells the story to a specific person or audience, which subjectively colors what form the story takes. Told to a different audience, the story would likely take a different form.

The third level is transcribing the narrative. Clandinin & Connelly, (1991) posited that interpretation of the narrative begins immediately, even in note-taking during or initial transcribing of the interview (see also Bell, 1999). The tape recording and the subsequent printed text of the spoken language are important not only for hearing and reading the story, but also to assist in consideration of language structures, pauses, emoting, repetition of words or themes, and other textual idiosyncrasies (Riessman, 1993). Meaning is communicated through speech patterns as well as through actual words; therefore, it is important that transcripts include nonlexical responses, such as *um*, *hum*, *uh* or other types of utterances (Chase, 1995; Riessman, 1993). An argument for excluding extraneous utterances is to improve textual clarity for the reader (See Clandinin & Connelly, 1991, for examples of narratives that do not include utterances).

At some point the researcher may want to design a story line about specific discrete narratives. Labov utilized a bounded story action and analyzed the common structures and sequences. Labov’s model posited that any “well-formed story” will have common elements: “…abstract for what follows (A), orient the listener (O), carry the
complicating action (CA), evaluate its meaning (E), and resolve the action (R)” (1972, 1982 as cited in Riessman, 1993, p. 59).

The fourth level is analysis, the creation of a metastory about the story. Riessman (1993) recommended beginning with examination of the narrative’s structure and organization, in an effort to avoid reading it purely for content or to find supporting evidence for prior theories. Repeated listening to the taped interviews in addition to re-readings of the transcripts, immersion in the data (Tesch, 1990), facilitated discovery of thematic content (Clandinin & Connelly, 2000). Additionally, the present interview content was considered in respect to the previously reviewed literature surrounding change, survivorship, growth, and meaning making in breast cancer. The goal was to seek themes supported by the literature, as well as to look for discrepancies that occurred in the stories. It is common with phenomenological data to interpret and analyze from the very first interview and proceed to go back and forth from data to analysis, over and over again (Tesch, 1990). Such an iterative approach with simultaneous data collection and data analysis is the recommended model (Ely, Vinz, Downing, & Anzul, 1997; Merriam, 1998, Tesch, 1990), because it enables the researcher to seek clarification and corroboration of common themes or discover exceptions and contradictions during the second interview. Maykut and Morehouse (1994) emphasized the importance of allowing for themes to emerge from the data, by discovery of recurring topics, words, or questions that appear.

With a case study approach, it is imperative to recognize that the understanding of the individual case is the primary concern (Merriam, 1998). In an attempt to provide a holistic understanding of the case, the single case reports should be rich in descriptive
information. The current research utilized individual case analysis with cross-case analyses to identify patterns that transcended individual cases. The cross-case analyses defined general explanations that unified themes across more than one participant. Once again, however, the researcher became very familiar with the data by frequent reading of and listening to the interviews (Maykut & Morehouse, 1994). Additionally, the analysis was conducted with a conscious attention to the literature and the themes previously reviewed in Chapter II.

Coding is that part of analysis that attempts to organize large amounts of data into manageable portions that thematically seem to go together (Ely, et al., 1997). Coding includes margin notes, highlighting of patterns and themes, clustering themes to make connections within and among different stories, and looking for plausibility and coherence (Huberman & Miles, 1998). The current research employed the computer software program NVivo 7 for the coding and analysis of the data content.

The last level in Riessman’s model is the final report of the research. The actual report of the current research includes themes of similarities and also disconfirming themes from the individual interviews. New information discovered should enhance counselors’ understanding and skills in working with breast cancer survivors based on what survivors shared about their lived experience. The opportunity to answer the questions “so what?” and “then what happened?” hopefully helped improve the lives of the survivors themselves (Miller & Crabtree, 2000).

Research Questions

The primary research question for the current study was to ascertain how the breast cancer survivor understood the meaning of her lived experience of breast cancer,
especially in ways that reflected changes in her life. A subcomponent of that was to
discover what actually changed, and whether or not the changes that occurred were
positive and growth-enhancing, or negative in nature. Additionally, some survivors were
able to articulate the dialectic of living with the reality of a chronic illness that may recur
at any time and what meaning that has for their lives.

The formal questions were as follows:

1) What has been the actual experience of breast cancer for the women who are
   survivors?
2) How have their lives been changed by the experience of breast cancer?
3) How do they understand the experience of coping with a chronic illness that may
   recur, and how has that impacted how they view themselves?
4) What meaning does the experience of breast cancer hold for their lives?

Institutional Review Board

Permission to conduct the research was requested and granted from the
institutional review board of The University of Akron. The consent is attached in
Appendix A. Under the jurisdiction of the IRB, the participants were informed of the
purposes of the study, the procedures of the interviews, and their rights and protections
under laws regulating human subject research. They provided written informed consent to
participate voluntarily, and the risks and benefits were explained to them. The steps taken
to insure their privacy were explained, especially in consideration of the audio taping of
the interviews. They selected a pseudonym for use during the taping, and the researcher
was the only one to know their true identity. After the acceptance of the study by the
Graduate School, the lists of pseudonyms and the tapes were destroyed. Participants were
given a printed list of available local resources should they need emotional support during or following the interviewing process (See Appendix E).

Chapter III Summary

The purpose of Chapter III was to describe the qualitative epistemology, strategies of inquiry, specific methods, and analytic approaches used in the current study of breast cancer survivors. This included a detailed description of the qualitative philosophy, including the epistemology of how knowledge is known. The strategies of inquiry focused on the use of a phenomenological, case study approach planned for the current research. Narrative analysis was the means to describe, interpret, and understand the stories told by the survivors. Ethical concerns regarding trustworthiness of the research and the researcher, as well as the IRB protection of the rights of human research subjects were also addressed. The following Chapter IV will present and discuss the research findings.
CHAPTER IV
DATA ANALYSIS

Introduction

“I know it is not like it was before – it will never be like it was before.” Riley

The focus of Chapter IV is to present the findings from the analysis of the interview data and how the data corresponded with the research questions identified in Chapter III. As stated earlier, the focus of the present qualitative research was to obtain plausible and coherent understandings of the phenomenon being studied (Raveis & Pretter, 2005), not to generalize the findings to all breast cancer survivors. Consequently, the narrative analysis of the data considered the stories of the survivors as the objects of the research (Riessman, 1993). The goal was to identify themes that either supported or disconfirmed the existing literature about breast cancer survivors, change, growth, and meaning. Just as the imagination and human agency of the participants guided what they chose to tell, as narrative researchers, it is the researcher’s agency and imagination that determines what is included in the written analysis of the data. The analysis then becomes the fourth level of representation in Riessman’s model of analysis (1993).

During the actual interview process, the participant-researcher interaction influenced what was shared. In telling their stories, they were co-creating self-identities as survivors and how they desired to be known. In reading the transcripts and listening to
the recording of their words, the researcher used a selective process of what to include in the final report, further co-creating their identities for the purpose of the research. Somewhat like a photographer or a *bricoleur* (Denzin & Lincoln, 2005), stories were selected, phrases were quoted, all for the purpose of description or identification of selected themes (Clandinin & Connelly, 2000; Riessman, 1993; Tesch, 1990).

The present research was a case study approach, and as such stories about each individual survivor were included in Chapter IV. Some preliminary chunking of the data and thematic analysis occurred at that step. The individual case reports were rich in description (Merriam, 1998), and one goal was for the reader to develop an initial acquaintance with the women themselves. As the analysis progressed, it was natural to consider cross-case comparisons, staying alert to patterns that transcended more than one case; for example, reaching out to others or giving back. Looking for key words from the stance of an informed reader and double checking with the participant helped to promote bracketing of the research (Janesick, 2000).

To strengthen plausibility of the results, a colleague from the counseling field assisted in identification of themes. This colleague had the demographic information of each participant as well as copies of the printed transcripts of the interviews. This procedure provided a form of member checking for the researcher or a form of investigator triangulation (Janesick, 2000).

NVivo 7 was the computer software used for the qualitative analysis of the research. It is a complex software program that aids in the organization of interview data into manageable nodes of thematic content and can be utilized to search for common words or phrases across the interviews. It has the capability to highlight portions of the
interview transcripts to make comparisons and clustering easier to find. NVivo 7 was used in addition to reading and listening to the words over and over. The actual analysis began with the first interview and continued throughout the entire process (Ely, et al., 1997).

As part of the iterative analytical process (Ely, et al., 1997; Merriam, 1998; Tesch, 1990) the semi-structured interview questions were used flexibly and with attention to the individual participants. For example, Janis seemed more concrete in her responses, and the more abstract questions of “what does it mean to you…?” were difficult for her to answer, necessitating more concrete follow up questions. Each participant eventually answered each question, but they were not presented in rigid order or manner (Denzin & Lincoln, 2005). As the interview progressed, the hope was that the stories would address the underlying questions of “so what?” and “then what happened?” in order to obtain the rich description desired.

The initial sections of Chapter IV discuss the research itself, the participants, the epistemology, the use of the researcher as instrument, and the phenomenon of breast cancer, with supporting portions of data that correspond with those topics. Additionally, examples of data are included that demonstrate how Riessman’s (1993) criteria of coherence—global, local, and themal—are supported in the analysis. The individual cases are presented next.

The Participants

The goal of the current research was to gain a deeper understanding of the phenomenon of breast cancer in the lives of survivors via the stories they shared with the researcher. The sample was not random, but purposeful with attention to maximum
variability. Participants were referred by a respected breast surgeon and by people who knew the researcher. One participant was a personal acquaintance of the researcher. Although all the participants were similar in that they had been diagnosed and treated for breast cancer within the past five years, they were dissimilar in many individual ways. For example, there were extremes of age at diagnosis: from 28 to 80. There was one woman who had had not only one recurrence, but was fighting her second recurrence at the time of the interview. At one point during the interviews, it was apparent that the women who were being referred were all white; therefore, the researcher contacted a colleague who is African American and requested possible referrals of women of color to enhance the maximum variability (Patton, 2002). There was less variability in socioeconomic status. The women were middle to upper middle class; all but one had had at least two years of college, two had graduate degrees, and most had worked in management positions or professional careers.

There were eight women who completed both interviews over a period of three months. One additional woman participated in a first interview, but objected to a second interview due to schedule constraints, so her data was not included in the analysis. The women lived in a Midwestern geographic area encompassing three different states. They came from major metropolitan cities, suburban and ethnic neighborhoods, and from rural communities. All had been married at one time, and one was currently divorced and single. Two have never had children. Of the three who have retired, two chose early retirement to take care of themselves or because work was no longer a priority in their lives. Two of the participants were African American, while the remaining ones were Caucasian. One woman was from a large Italian family and lived in an older Italian
neighborhood. Four of the participants defined themselves as coming from a strong Christian faith perspective, and two of those were in visible positions of leadership within their respective churches. Ages ranged from 28 to 80 at time of diagnosis, and current ages ranged from 31 to 80.

Family history is an area of concern within the breast cancer survivor community, although the literature supports that 90-95% of newly diagnosed women have no family history and 75% have no known risk factors (Keitel & Kopala, 2000; McPherson et al., 2000). Interestingly, however, all but two of the survivors interviewed did have some family history of breast cancer. Two of their mothers had been treated for breast cancer in their sixties; one mother died from a stroke in her eighties and the other is still living, currently in her 70s. Three others have had non-first-degree relatives (aunts and cousins) with breast cancer. Three of the women have had the genetic testing for BRCA 1 and 2 genes with negative results. One woman has a very strong family history of breast cancer (see Olivia, below), with a grandmother who died of breast cancer, and two sisters who are also breast cancer survivors. Her mother died by suicide, but the oncologist and geneticist both agreed that it was likely her mother would have or did have breast cancer due to the genetic studies they have completed. Although negative for the BRCA genes, Olivia and her sisters have had additional genetic testing and counseling, and they are reported to carry many of the risk factor markers, including incidence of melanoma, for hereditary breast cancer (Weitzen, Harari, Achiron, Catane, Mandel, 2004).

Treatment options ranged from surgery alone, to surgery plus radiation and/or chemotherapy. Some are currently on hormonal therapy post initial treatment. Four selected breast-conserving lumpectomies, while two had single mastectomies. Two
women opted for prophylactic bilateral mastectomies, and one plans to have a prophylactic second mastectomy as soon as she is six months post radiation.
One participant had experienced a second primary cancer 19 years after having her first breast cancer, and it was after the second episode that she volunteered for the study.
Another woman is currently undergoing treatment for Stage IV metastatic breast cancer which had recurred twice since her initial primary diagnosis.

In accordance with the methodology parameters established in Chapter III, all of the survivors had completed initial treatment (surgery, radiation, chemotherapy) but were within the first five years after diagnosis. The shortest interval since diagnosis was ten months, and the longest was just a few months short of the five years. The participants did demonstrate a strong degree of maximum variability in race, age, geography, degree of severity of disease, and treatment modalities (Patton, 2002).

*Interviewing Participants*

As referrals were received, the researcher telephoned each woman and briefly explained the procedures of the research, the purpose, and scheduled a time and location for the first meeting. Each participant agreed to two interviews that were held approximately three to four weeks apart in locations they selected. One woman chose to meet in a local coffee shop and was unconcerned about any loss of privacy; the others met in their homes, most often sitting at the dining room or kitchen table. A few times, family members were present, but not within conversational range. At the first interview, the informed consent was discussed, and participants had an opportunity to ask any questions they might have. The voluntary nature of the research participation was carefully explained, as well as the need for two separate interviews. At the second
interview, each woman received a $15 gift card to a store specializing in body care products, as specified in the informed consent. Additionally, the researcher gave each one a pink rose to thank her for her help. Typically, first interviews lasted slightly over one and one half hours, and most of the actual interview content was covered during that first meeting. Second interviews were shorter, usually less than an hour, and allowed for clarification, additional thoughts, and a solidifying of the relationship between researcher and participant (Denzin & Lincoln, 2005). Additionally, the opportunity to verify the researcher’s understanding of the previous account strengthened the plausibility of the research (Riessman, 1993).

**Self as Instrument**

To enhance the interactive relationship, I attempted to be open and genuine, to treat each participant with unconditional regard, to listen empathically, and to value her and her story (Rew, et al., 1993). The interview guide (See Appendix F) consisted of semi-structured questions. True to my training as a counselor, and with support of Denzin & Lincoln’s (2005) stance that the researcher must adjust and adapt to the emerging story, I followed the questions flexibly, allowing the stories to flow, without asking the questions in a rigid or rote manner. Ultimately, each participant addressed the content of each interview question.

One participant (Janis) was somewhat difficult to interview at the first meeting. I noticed that she did not make eye contact when she spoke, her voice and affect were slightly flat, and she did not appear to be very self-reflective. Rather, her answers were more factual and impersonal in nature, often referring to her cancer as “it” or “the thing.” She has survived breast cancer twice now, and her comment was that “cancer was no big
deal” the first time around. She also appeared to minimize the seriousness of her situation, because she did “not have a radical,” reflecting that sense of “motivated self-enhancement,” finding someone worse off than herself to feel better about her own situation (Park, 2004, p. 71). Her advice to someone else would be to “get it taken care of…then get on with your life. You can’t just crawl in a corner some place and be sorry for yourself.” My initial reaction to her interview was to consider that this might be a generational response. Janis is 80, and she did not ask many questions about her treatment and seemed willing to do what the doctors advised, consistent with findings that older women frequently do not seek second opinions or additional information, but tend to prefer less active involvement in decision making (Petrisek, Laliberte, Allen, & Mor, 1997). She additionally emphasized her “work ethic” upbringing and stated that she did not want to become a burden to anyone or have anyone have to take care of her (Manne, et al., 2004), a common concern of a person with a chronic illness.

Upon further contemplation of her comments, I concluded that her illness story had been lost in the overwhelming story of her husband’s life-threatening illness that occurred the year before her breast cancer. This was confirmed when at her second interview she volunteered that she had been feeling “not depression exactly, but sadness” at thinking about all she had been through. Apparently her style had been to keep busy without taking time to think, and thus she subsumed her illness response within the story of her husband’s. I surmised that my empathic listening and willingness to hear her story enabled her to think to some extent about her breast cancer.
Epistemology

Janis further illustrated the epistemological perspective of the research: to consider the socially constructed knowledge about the breast cancer experience within the context of the person living it (Creswell, 2003; Livneh & Antonak, 2005; Merriam, 1998). The subjective meaning for Janis was that she has spent her married life taking care of her husband: “I am so busy cooking for my husband and doing all of the chores around here…” When he nearly died following heart surgery, and then spent months incapacitated, she focused all her energies on his recovery. Since her first breast cancer had been while she was in graduate school, and she had returned immediately to school after the surgery, she considered breast cancer as “no big deal,” especially in light of his serious heart problems. Puzzled by the fatigue following her present surgery and radiation, she kept on pushing, taking pride in the fact that she had taken “only two naps” during her recovery and determined to not become a “burden.” My sense was that she actually reflected for the first time on what her breast cancer meant to her during our interviews.

Claire is another example of the need to contextualize understanding her illness experience within the context of her life history (Shapiro, Angus, & Davis, 1997). College educated, she chose to stay at home with their daughter and to be actively involved in her husband’s ministry, rather than focusing on a career. Twenty-eight years old when she was diagnosed for the first time, she remarked that the significance of breast cancer paled in comparison to the experience of becoming pregnant after infertility treatments, and giving birth to twins at 28 weeks gestation, one of whom died at birth. Additionally, her husband’s mother had died of terminal brain cancer three weeks before
Claire gave birth. Her statement, “I think, really, going through the breast cancer wasn’t as hard as losing a child” makes more sense when considered in the context that Claire stated “all I wanted—was to be a mom and have a few kids, and you, know, and everything was taken away from me…I felt like…our daughter who passed away—that was taken away from me too.”

**Phenomenon of Breast Cancer**

Understanding the essence of the experience of breast cancer as lived by the participants was an important goal of the research (Creswell, 2003; Schwandt, 2000). Although there were some commonalities (e.g., recovery from surgery and adjuvant treatments, fears of recurrence, life upheavals), the subjective nature of each woman’s breast cancer was different. My desire was to listen for the uniqueness and the differences, according to Chase (2005), valuing the specific meaning of each woman’s cancer, rather than looking for generalizations (Raveis & Pretter, 2004). For Claire, breast cancer has ultimately meant post chemotherapy infertility, a hard loss for the woman who desperately wanted just to be a mom. Her breast cancer has been subsumed within her story of greater loss.

For Olivia, breast cancer in herself has little meaning, other than “I was lucky.” One of four daughters, Olivia is the third sister to develop breast cancer. Hers was very early and small, but she elected to have bilateral prophylactic mastectomies with reconstruction due to her family history. Since her two sisters had more extensive disease and suffered noxious treatment side effects, she considers herself lucky to have escaped radiation and chemotherapy. Even though her grandmother died of breast cancer, and she and her two sisters have had breast cancer, she truly believes that she is out of the woods
and she is “over and done with it.” For her, there is no daily reminder that she is a
survivor, and she does not view herself as a person with a chronic illness.

Gretchen, another survivor, viewed her breast cancer within the context of cold,
impersonal medical treatment, coupled with not having anyone to be with her. She
described receiving the phone call that the biopsy was malignant while she was home
alone. The doctor merely told her “you have breast cancer…so we’ll get back to you with
a surgery opening” without asking her if she had anyone with her or inviting questions.
Then she had to wait for six weeks before she could have her surgery. Although her son
was with her during the surgery, he lives elsewhere and could not stay. Divorced, with
both sons living out of town, she stayed in her condominium for days, alone. Her
experience of breast cancer was one in which no one brought food, or even called her “to
take me out to eat.” In the back of her mind was the question “where are the friends?”
The loneliness of her recovery has precipitated her decision to move closer to one of her
sons, leaving the rural area where she has lived all her life. For her the phenomenon of
breast cancer is within the context of facing a crisis by herself.

As part of the phenomenological approach, Riessman (1993) described three
constructs of coherence (See Chapter III). Olivia provided an example of global
coherence (overall goal and justification for specific actions). After a ten year history of
frequent breast cysts and four biopsies, this time the doctors recommended bilateral
mastectomies, given her history and the amount of atypical cells. She went into great
detail, describing the familial history, the genetic and genealogical counseling they
underwent, her process of seeking second and third opinions on surgical options:
but we hit every [genetic risk] marker. So they just said they would strongly recommend that I have a prophylactic mastectomy and they wanted me to see an oncologist right away. So I saw a couple of oncologists right away. I went and got another opinion. I went to my family doctor. I went to my obstetrician. You know, they said “you have this many days so go and get some other opinions.” He was very well known, like I said that was all he did – he was a breast oncologist and that was his strong opinion. So I did, I went to all those doctors and everybody thought with all of our history and background and with my pathology from my lumpectomy, just because of the size and that there was so much atypical in there, they really felt I should have a prophylactic mastectomy.

Olivia went on to describe that it had taken her six months to finally agree to having the mastectomies, and that “it was probably the hardest decision I have ever made in my life.” She told how her one sister so far unaffected by breast cancer was adamantly opposed to the decision, and reacted very negatively, withdrawing her emotional support. Then Olivia expressed her great relief when the final pathology report showed active cancer in one breast, undiagnosed on the mammogram. I had a sense that she was justifying to me, and perhaps herself, that the decision she had made to go with prophylactic mastectomies had been the correct one after all.

Riessman’s (1993) local coherence (temporal arrangement, style, and emphasis) was illustrated by Annie’s story. When asked at the very beginning to tell about her breast cancer, she remarked

I think I have to go back to my friend Mary who had breast cancer a year before me. We went to high school together, we played rugby together, we got married within 2 months of each other, we had our first child within 2 months of each other, and we had our 2nd child within 2 months of each other, so we had a lot in common – very close. My husband and I lived out in California for 5 years but when we moved back we reunited with them. We are closer with them than we were before we went to California. Mary went on and had 2 more children. I stopped at 2. But she was diagnosed with breast cancer 1 year before I was and I went through her experience with her, so I think I was better prepared because of that and I think my children were also. But almost a year to the date, I found a lump in my breast.
Her story was thematically and chronologically linked with the mirroring of her friend’s life and breast cancer experience, and then another friend’s diagnosis the following year. Throughout her interviews, she was a master story-teller, and her stories epitomized the concept of rich description. She described how she had lead a Relay for Life team for her friend, who in turn led the team the next year for Annie, and together they led a team this past year for another friend, newly diagnosed with breast cancer, “…we did a newspaper article for our Relay for Life team – it was Mary and I and then Ellen, who has just been through one chemotherapy treatment. So when you get 3 breast cancer women, we all have this lingo – it’s like ‘did you do this’ or ‘when did you lose your hair?’”

Thematic coherence, re-occurring themes within and across participant stories, is also important (Riessman, 1993). Again, using Annie to illustrate, the theme of her friends going through breast cancer before and after she went through it is throughout her interviews. A subtheme of that is her willingness to reach out to sister survivors, through the Relay for Life, through taking small necklaces symbolizing hope to someone newly diagnosed, and through a list of 25 women survivors she prays for daily.

With Olivia, there is a continuous theme of what her experience has been like to see two sisters going through breast cancer, “going through the pain, the fear, the…everything and it was scary…I watched my one sister go through chemotherapy, we took turns to fly out to be with her during the chemotherapy and stuff and she was so sick.” With Bonnie, there was a frequent theme of not having anyone to help her. She began by sharing how she had been there for her mother when she was diagnosed with breast cancer several years ago. Then when Bonnie herself had breast cancer, her mother
wasn’t really there for her, and she felt all alone. She mentioned her husband did not initially give her help around the house, nor did her friends. A current of disappointment and anger permeated her stories. She even prayed that she would “get through this and to deal with the people” because “I can still get angry” about the lack of support.

There were other consistent themes that appeared in more than one narrative, such as the lack of supportive help from others, a change in life priorities, an urge to reach out to others, and changes in relationships. These will be discussed more fully in the following sections. The fact that there are repeating themes provides support for the credibility that certain needs and concerns of breast cancer survivors have been identified.

Research Questions

The purpose of the research was to ascertain how breast cancer survivors understood their lived experience of breast cancer and how change had manifested in their lives through their journeys. The specific questions are considered below:

1) What has been the actual experience of breast cancer for the women who are survivors?

2) How have their lives been changed by the experience of breast cancer?

3) How do they understand the experience of coping with a chronic illness that may recur, and how has that impacted how they view themselves?

4) What meaning does the experience of breast cancer hold for their lives?

Question 1: What Survivors Experienced

All of the survivors interviewed reported that they had changed during their breast cancer experience, and they easily compartmentalized their lives into “before” and “after”
cancer (Calhoun & Tedeschi, 2006; Miller, 2004). However, none of them had experienced the type of watershed event called quantum change (Miller & C’de Baca, 2001) as described in the literature. They experienced the scare of finding a lump or having a suspicious mammogram, the fear while waiting for biopsy reports, and the physical trauma of surgery and possibly radiation or chemotherapy. They were subjected to that rapid entry into the health care system with its accompanying pressure to make complex decisions without prior medical experience (with the exception of Bonnie, a nurse). Olivia was the only one who had the luxury of taking time to research and consider many different options; everyone else had to move fairly quickly into making treatment decisions. Some had good experiences with their treatment teams (Annie, Riley), while Gretchen was treated extremely poorly by her doctors. Many of the women reported supportive friends and family members, but a few felt neglected and uncared about.

They all reported widely varying moods, including fearful, sad or depressed, angry, and even joyful. They described both physical and emotional changes. Self worth and self confidence fluctuated as they struggled with the change in physical appearance and sense of well-being. Treatment effects were described by all eight of the women. Some demonstrated a great deal of eagerness to find out all about their cancer and their options (Olivia), while some allowed others to make all the necessary plans without questioning them (Janis).

**Question 2: How Survivors Changed**

The women reported changes in all domains of their lives: physical, emotional, relational, social, and spiritual. Many reported dramatic changes in areas such
as lifestyle (Riley, Claire), values (Janis, Olivia), priorities (Marie, Annie), and relationships (Bonnie, Gretchen, Olivia). Many reported support for the themes identified in the literature, such as changes in relationships or changes in priorities. Additionally, they reported both positive and negative changes. Although many changes were remarkable, with shifts in values and thinking (Olivia, Claire) (Miller, 2004), it appeared that their experiences of change have occurred via a slower process. It is possible that some were still experiencing the early stages of ruminative cognitive processing described by Calhoun and Tedeschi (2006), and that they have not yet arrived at a level of meaning reconstruction for their cancer (Neimeyer, 2006) (Riley, Janis).

Two women have had dramatic changes with the addition of new children following their cancer (Marie, Claire). They shared that they were concerned about the possibility of dying and talked openly of considering how to best make sure their little ones would know their mommies if they died. Two women have retired by choice, in order to promote their own health and to have time for what was important to them.

They talked openly about the physical changes resulting from surgery and treatment. Several experienced altered body image and physical limitations. A few reported sexual dissatisfaction, either from physical changes or changes in their self image which made intimacy difficult (Claire, Riley, Gretchen). They described losing their hair from chemotherapy. Marie went bald to school: the inner city school where she taught prohibited students from wearing hats or dew rags, and since she disliked the feel of a wig, she went without. Annie described how important it was to her to look like herself, so she chose a wig as close to her natural hair as possible. They described skin
changes from radiation: Gretchen described experiencing burning, and smelling burnt flesh every day, and being unhappy with the discoloration of her affected skin to this day.

The women lost friends and gained friends; they had supportive husbands (Riley, Olivia, Claire) or they had husbands who expected their prior level of functioning around the home (Janis, Bonnie). They reached out to others (Annie) or they chose to take care of themselves first (Bonnie) instead of being the constant care-taker for others. Some reported a deepening of faith or spirituality (Marie, Annie), while others questioned what God had done (Claire).

Priorities and life goals changed, with comments about letting the “little junk fall away” or “living in the now.” Annie described the sweetness of sitting outside enjoying smelling the flowers and listening to the birds. Riley mentioned enjoying sitting in silent companionship with her husband and not feeling that they should be “doing something.” Marie and Claire both wanted children: Marie became pregnant, and Claire adopted a toddler from China. Annie talked about the importance of having a sense of humor, and shared how they nicknamed her wig Madge.

Question 3: How Survivors Understood Chronic Illness

The women were not all convinced that they were experiencing a chronic illness. Although they nearly all agreed in principle that breast cancer could be considered a chronic illness, they did not all believe that the chronic illness label applied to them. Olivia was very firm in her belief that she did not have a chronic illness. She felt that she had been treated successfully and that she had beaten the cancer and moved on. Contrasting her experience with that of her two sisters who have had breast cancer, she could agree that her one sister’s was a chronic illness. That sister had had aggressive
treatment for an advanced cancer, and she had experienced many aversive after effects. Olivia agreed that that sister had a chronic illness. Even acknowledging that one of the criteria for chronic illness was that there was no cure, Olivia still believed hers was gone.

Others would acknowledge that the physical changes (for example, hot flashes, joint stiffness, lowered stamina) seemed to indicate chronic illness, it just was not a concept that they seemed to associate with themselves. Although they all mentioned an increase in anxiety when they had their checkups with the oncologists or went in for their mammograms: at those times, they personalized the reality that recurrence was always possible. Riley described living with that “bit of fear” that it could come back, but not “letting that run my life.” It appeared that most of them were seeking that balance of living life under the shadow of possible recurrence, but going on about their daily lives as normally as possible.

**Question 4: Survivors’ Experience of Meaning**

All the women interviewed grappled with doubts and questions and attempted to understand their breast cancer. A couple stated that they never questioned God why breast cancer happened to them, because of their particular upbringing; two of them, however, did question God, and reported being angry with him for allowing this in their lives. For Claire, one meaning of chemotherapy had been the inability to conceive, which greatly increased her angst. Claire, Riley, and Marie provided support for that shattering of world assumptions described by Janoff-Bulman (2004), with comments about loss of innocence and living good lives while experiencing bad things.

The participants were at differing stages of meaning making in their breast cancer experience. Janis really had not thought or talked much about her two incidents of breast
cancer. Niemeyer (2004, 2006) posited that meaning is derived from telling a story about the traumatic experience (see also Collie & Long, 2005; Schwind, 2003). Additionally, trauma is often not talked about at first, partly because the person is unwilling to consciously consider what happened (Collett, 1998). It seemed likely that Janis needed to allow herself to reflect and ruminate cognitively (Calhoun & Tedeschi, 2006) in order to derive meaning for herself. Annie, the master story teller, constructed her stories into methodical sequence as she communicated to me what her experience meant (Josselson, 1995; Niemeyer, 2004). Riley metaphorically (Bateson, as cited in Clandinin & Connelly, 2000) compared her experience to war: “in the trenches,” the “general [doctor],” and “courage to fight.”

In summary, the survivors’ stories illustrated and supported three of the research questions: one, two, and four. However, the one question about chronic illness (three) did not seem to be as supported in their particular lives, even though they accepted the intellectual concept that breast cancer was a chronic illness.

Case Study Examples

Each individual participant was considered as a case study entity on her own. Although time limited to the five years following their diagnosis of breast cancer, it was possible to learn much about the participants’ lives, values, and experiences from the stories they shared. Although how and why questions are most common with a case study approach (Yin, 1994), most of the women did not spend much time on the why of their breast cancer. However, they were more than willing to share the how: how they discovered it, how the treatment went, how they’ve survived, and especially how they
have changed. Following are brief case analyses, or mini snapshots, of the eight participants.

Bitter Or Better: Annie

Annie lives with her husband and two teenagers in a century home in a rural community not far from a mid-sized city. She has two sisters and a brother with whom she is close, and her parents live nearby. Annie was 45 when she was diagnosed with breast cancer three years ago. Her life mirrors the story of her high school friend, Mary. Not only did they go to school together and play rugby together, they married within two months of each other, had their children at about the same times, and have remained close friends. Although Annie and her family lived out west for several years, they now live just houses away from each other. Mary was diagnosed with breast cancer a year before Annie’s diagnosis, and Annie recognizes how much she learned from her friend’s journey. She also believes it helped her two teenagers to have seen their friends’ mom coping with this disease and having a good outcome.

Annie found her lump on her wedding anniversary just before the Christmas holidays, but ignored it until January. At that time, her doctor ordered a mammogram, followed by an ultrasound and a needle biopsy. She described finding out about her biopsy results on the Monday following the Super Bowl:

That was the Super Bowl where Janet Jackson exposed her breast…So that Monday I was waiting for the pathology report to come back from my biopsy and as I was waiting I was watching TV and all you heard about was Janet Jackson’s breast and…oh my gosh!

Her treatment involved a lumpectomy followed by chemotherapy and radiation, because she wanted to be as aggressive as possible. Her recovery was complicated by low
blood counts and one fairly serious infection requiring hospitalization. A preschool speech pathologist, there were times she could go to work, but was not allowed to see any of the children, due to the possible risk of acquiring an infection.

One of the poignant aspects of her journey was her story about her mother’s current battle with Alzheimer’s. Annie and her father had decided that they were not going to tell her mother that Annie had breast cancer. The day after Annie’s surgery, her parents came over for a visit. As she told it

I had a little sweat suit that I got that zipped up the front. So I got up and I put makeup on and I sat in a chair, because I didn’t want my mom to know that I had been through surgery. At this point she was very “in and out”, you know, didn’t know or understand too much…

She proceeded to talk about how her mom used to be a big shopper and would have lavished Annie with hats and wigs had she known about the cancer, telling her sister, “You know if Mom were still well, I would have 50 hats on this bed right now…and I would probably have 10 wigs.” And then she stated that although she really needed to protect her mother at this time, “…sometimes, I just needed a mom.” At this point, eyes tearing up, her voice wistful, she expressed that her mother would have been a great support for her and would have been terribly hurt knowing Annie had cancer, and I heard her longing to be cared for by her mother.

Annie described herself as a Christian and talked about how important prayer had been in her healing journey. She also mentioned her involvement with the local Relay for Life, heading up a team first for her friend, Mary, then for herself, and recently this past year for another friend who is newly diagnosed with breast cancer. Her comment about breast cancer was from a quote she recalled, that cancer can either make one bitter or
better. To her this meant that she chose not to become bitter and focused on what she had lost, or her potential for a shortened lifespan, but to be grateful for what she still had, to learn to rely on God, and to be willing to reach out to others. It was hard not to contrast this with Bonnie’s story (below). The two women had strikingly different reactions and moods in response to their experiences. I felt Annie more closely illustrated the posttraumatic growth domains concerning altruism, compassion, and that greater appreciation of her faith and purpose.

Prayer’s Important But Offer To Help: Bonnie

Bonnie, 50 years old, had just changed from her full-time nursing management position with Visiting Nurse Service to part-time when she discovered her breast lump in June. As a nurse who watched her mother go through breast cancer several years ago, she was pretty convinced it would be cancer. Her immediate concern was her eight-year-old daughter and whether she would be able to keep up with all her “little events.” Bonnie admitted to being angry, because this was to be her first summer not working, and her husband had just added a new deck and gazebo on to their suburban home. They had lots of plans for the upcoming summer. Two years later, Bonnie made the decision to take an early retirement, and she was eagerly anticipating being free for the first time during the summer.

Bonnie was a referral from a mutually known African American colleague whom I called to ask for possible referrals of women of color who might participate in the current research. Bonnie was very willing to talk to me, and my nursing background as well as my survivor background seemed to make her feel comfortable. Articulate, humorous, and very knowledgeable, there were times during the first interview when she
was a bit quieter and less forthcoming, until her husband left to go to work; then she seemed to become more open and frank. She volunteered that she requested treatment “as aggressive as possible, as I have a kid to raise,” and she opted for both chemotherapy and radiation.

She eagerly compared her mother’s experience with her own. Not only was the treatment more extensive in her own case, but she had been her mother’s “advocate and nurse,” and she stated she “felt pretty alone” in facing her cancer treatment. She experienced little support from friends or family which greatly disappointed her. She remarked that initially even her husband was not very supportive, and she described a more traditional family life in which all the household and child rearing duties had been hers. “You know, it’s almost like you are not allowed to be sick. You know, you’re just not—you can’t be sick—you really can’t.” Her altered physical condition seemed to be disregarded by family who continued to expect her to be the planner and doer of the family.

She expressed feeling disappointed at her lack of support. She somewhat excused her mother, “because she is elderly,” but even her friends failed to meet her expectations. Belonging to a large African American church, she mostly received statements of “I’m praying for you” rather than offers of actual help, which disappointed her greatly. She described the need to draw upon her own faith and inner strength and do for herself. Now two years later, she felt she was just beginning to heal from the “hurt.”

Bonnie attributed her stronger, more vital faith to this experience, since all she could do is to go:
to my prayer closet and [get] down and I just prayed and I said ‘Lord, just help me get through it and to deal with the people’ because I could have been very angry and I still can get angry…I needed to say to myself ‘This is what happened, ok, but you are still a good person and you can still make it, even if you have to do it yourself’…I never have really confronted or said anything to anyone—except you—that I didn’t feel people supported me very well during that whole time.

Drawing upon an earlier miscarriage, Bonnie used what she learned at that time to help her cope with the hurt and disappointment. She felt that both of these experiences had likely made her more sensitive and compassionate to others who were in difficulties. She stated that the main thing she learned was not to say “if you need something, give me a call” but to offer concrete help. One of her long-term ideas is to write a booklet for friends and family of women with breast cancer, instructing them about the kinds of helpful things they might do.

Other changes she has experienced since her cancer include a change in priorities, especially in putting care for herself first, and learning to live differently. She is looking forward to being retired and less scheduled, taking time to do things she wants to do, and being less perfectionistic about keeping her home in order. Another interesting comment she made was that she thought she had matured as a person during this time, learning to take one day at a time, and interestingly enough, desiring to reach out to others and give of herself once she has rested and enjoyed some free time. Her comment was “You want to make sure you have done all you need to do.”

At the conclusion of her second interview, she handed me a hand-written note (her daughter was home, playing upstairs) indicating that she had found another lump, had had a biopsy, and that the doctor was hopeful it was not cancerous. She was anxious,
and I recognized that the fear of cancer will rear its ugly head when we least expect it, and that for the survivor, that fear never leaves.

Where Are The Friends?: Gretchen

Gretchen is an energetic and enthusiastic 65 year old African American retired and divorced woman who has lived in the same rural community all her life. She has two grown sons who have moved away. She is looking for a condominium near one son, making plans to move within the next year or so. Going through her breast cancer experience basically alone has made her want to live closer to her son. Her treatment was surgery and radiation, and she mentioned she was not sure she should do the interview, as she had “only” had the radiation, not any chemotherapy.

Gretchen’s mother had breast cancer at the age of 70, but died at 88 from a stroke, just the month before Gretchen’s cancer was discovered. She described how she had recently retired from working at the utility company, and her mother’s stroke occurred the day before her retirement. She spent time with her mother in the nursing home daily for two years. Then newly bereaved, she found out she had breast cancer.

Finding out about her cancer was an unpleasant experience for Gretchen. She had gone for her mammogram at a large medical center over an hour away, and had plans to meet a friend for lunch afterwards. When the mammogram looked suspicious, the doctor did a biopsy that day after a two hour wait, and then she had to drive home by herself. The doctor did tell her however, that it did not look like cancer, and that it was probably nothing to worry about. Three days later, alone in her condominium, she received her results by phone. “I was sitting here by myself, watching TV, and Dr. (I forget her name) called and she said… ‘you have breast cancer…so we will get back to you with a surgery
opening.’” Gretchen was upset and alone, and felt the doctor had been cold and uncaring, never asking if she had someone with her. She spent the next three days by herself at home, not leaving and not willing to talk to anyone as she was not ready to share the news yet. She stated that she read the Bible constantly, and that that was what helped her get through those days.

She had to wait for six weeks for her surgery, and she described a cold and impersonal experience:

Yes, my son came in…and he went with me and you go into a room and you sit in this easy back chair and they give you this space suit…(chuckle)...yeah, it looked like one. And then when they come to get you, they walk you into the surgery room and you get up on the table, and then they bring you back and take you to your easy chair and then you come home. So that was so different…There wasn’t any bedside manner or anybody come in to talk to you or anything—you are just, you know, there.

When asked if she had been changed by her cancer, she immediately named her increased faith and a change in relationships. She stated that she began going to church more often and more regularly and reading the Bible more. She never questioned God why this had to happen, because of the teaching of her grandfather, a minister, who taught her “You can’t say, ‘why me?’ because God will only say, ‘why not you?’” Prayer and time reading the Bible were what helped her most.

As to relationships, she clarified she meant relationships with men:

Uhm (pause)...I had relationships, you know, with men, but it changed. It was like, (chuckle) I don’t want them touching, you know—and I don’t know if they felt the same way, but sex just wasn’t the same anymore. I don’t know if it is me, but to me that was it... I still have a couple friends, but I keep them at bay...you know, going out to eat...or coming over and sitting...there is not that intimacy there...
She went on to say that she wondered if she were married, if it would be different, but that she felt protective of her still tender breast, and she was reluctant to make herself that “vulnerable.” She also mentioned that this was a negative change and a part of her life that she was missing.

Additionally she mentioned the lack of support she had experienced, especially from church friends, and that this was partly behind her plans to move near her son. No one brought over any food or “came over to take me out to eat,” and she was surprised. She thought her friends were close, but apparently “they weren’t willing to be that close.” She described breast cancer as not being the kind of “sickness where you go to bed and be sick, you know” and speculated that for her it was more mental than physical—a time she would have liked to have had people around. Her comment was that she “didn’t get mad, didn’t get upset, didn’t say anything—but it was in the back of my mind—where are the friends?”

I Don’t Want To Be A Burden: Janis

Janis is a youthful looking 80 year old lady with beautiful perfectly coiffed silver hair. In fact, she stated that her hair is the one thing that would have kept her from agreeing to take chemotherapy, because it was her one vanity. Her cancer had not spread to any lymph nodes, so she had a lumpectomy and radiation. When I met her, it was not quite a year since her diagnosis. Interestingly, this was a second primary breast cancer for Janis: she had had breast cancer in the other side when she was 61. With that cancer, the only treatment she had was surgical.

Janis and her 85 year old retired husband have lived in the area all their married life; although two years ago they moved into a condominium in an adjoining suburb.
Janis did not attend college until she was in her 50s, and her initial breast cancer occurred while she was in graduate school in 1987. With surgery scheduled over spring break, she returned to school immediately afterwards. Her comment was “I don’t know that it affected me any because I went right back to school, you know.”

Janis was soft-spoken, with a rather flat tone and affect, and she made little eye contact as she spoke. She tended to answer questions and stay with more factual revelation rather than emotional. An interesting observation I made was that Janis tended to speak about her cancer in impersonal terms, “it” or “the thing.” However, she was pleasant and hospitable, serving homemade lemonade and apricot bars at the second interview, and she was a bit more talkative and somewhat livelier during that interview. This might have been a generational effect, with some reserve about sharing personal information with a stranger, or some guardedness against emotional disclosure, or perhaps a personality trait. However, my speculation is that she had not ever really thought much about her two experiences with breast cancer, most especially how she felt during diagnosis, treatment, and recovery. To Janis, her first cancer was “no big deal,” and she recalled that having her tonsils removed had been more painful than the lumpectomy. In her words, “The first time, I had so many things going; I don’t think I really realized what was happening.” She also alluded to some regret in not being more available or helpful to friends who had gone through breast cancer or illness, stating “I have another friend, and I’m sorry I was not sympathetic to her at the time—I think it is because I had so many things going, but she had a radical…”

She mentioned her “work ethic” upbringing, and how it was sinful to watch television before getting your work done. She spoke about refusing to take naps during
her recovery, “I think …I only took two naps” and yet she spoke often about the great fatigue she had experienced. She described a more stereotypical wife’s role of “doing everything” even though she always worked or was in school. At the second interview, she stated that she had given much more thought to what she had been through, “So I have had a lot to think about and uhh...why did this…I never thought when I was going through it, why did this happen to me, but now I am starting to.”

Tentatively wondering if perhaps she might be feeling some depression, or “not depression exactly, but sadness”, we took some time for her to consider all that had changed—their move, her husband’s recent serious heart problems, her breast cancer, and her feelings of loneliness and homesickness for her nieces and nephews who weren’t calling or visiting, all complicated by her post-recovery fatigue that she didn’t want to allow for. She agreed that she typically would just keep too busy to think about difficulties, a skill she had learned growing up in a single parent family with a lot of neglect and a “mean mother.” She also had concluded that this time, however, her fatigue and the other circumstances of life “made it a big deal” even though she attempted to minimize it by stating she had not had a radical, so it wasn’t as bad as some women go through.

When I asked her what it meant to her to be a breast cancer survivor, her reply was interesting. Originally her opinion had been that a survivor had had a “very bad cancer” like a “radical,” although she now thought anyone with breast cancer could be a survivor. I then asked her what that meant to her, and her reply focused on her desire not to become a burden to others.
I was determined to get over it, to recover, and mainly to not be a burden to my
husband or my family. So my attitude was, I am going to get over this and I am
going to cause as little upset in everybody’s routine as I could…Nobody is going
to have to get my meals or do my clothes or whatever.

To me, a significant story was the story about her husband’s serious heart
surgeries and near-death episodes. It appeared that she attributed her breast cancer onset
as a possible result of the stress she experienced during his crises. Even though she was
the primary homemaker before this, she stated this experience changed her: “I changed
and I learned that I couldn’t do everything that I had to do because I had to take care of
my husband.” It seemed during the interviews that her illness had become subsumed
within the story of her husband’s.

Bittersweet: Marie

When I arrived at Marie’s home, her six-week-old miracle daughter was sleeping
in the baby swing. Conceived after completion of chemotherapy and radiation, the baby
is Marie’s reason to live, and Marie is recording each day with her digital camera,
building a scrapbook for the baby. Diagnosed with breast cancer at the age of 28, there
were days when Marie believed she would never have a baby. She was the youngest
breast cancer patient to harvest eggs prior to chemotherapy at the invitro clinic: they told
her when she would come in, she was known as the “28 year old with breast cancer” and
“no one wanted to hear bad news” about her. Her first egg implant did not take, but she
and her husband conceived the very next month on their own, and she considers that
amazing.

Marie is a high school health teacher and coach, and every year she presents a unit
on breast and testicular cancer. She mentioned that she never did breast self exams
because she was so young, but one month, on a whim she examined her breasts. To her amazement, she felt a lump which proved to be cancerous. Fast-growing, over the three month period it took to conclusively diagnose it, it grew from pea-sized to a stage II-B cancer. All the while, her doctors were telling her she was too young for it to really be cancer.

Marie is Caucasian, married for only three years at the time of her breast cancer, and she lives with her husband, baby, and cat in an older neighborhood in a suburb of a large city. She teaches full-time, manages a local swimming pool full-time during the summers, coaches different teams, and runs. Additionally, she is in graduate school in a behavioral science field. She mentioned she wishes she could leave her job now that they have the baby, but she really cannot quit.

Stating “you can’t prevent it from happening,” she and her husband are trying hard to prevent a recurrence of breast cancer. They have changed their diet; they have eliminated chemicals and bleach in laundry and cleaning products, all in an attempt to alter their environment. She spoke of the injustice of her cancer:

I am an avid runner and I was always very healthy, and from all of the people in my family, I am the one who gets cancer when there are people who smoke and drink and they probably have never exercised a day in their life and then, here’s me…

Having breast cancer and having a daughter have caused Marie to re-evaluate her difficult relationship with her mother who has a mental illness. Since she has never had a nurturing relationship with her mother, she does not feel as though she missed anything during her cancer. She did, however, spend a significant amount of time during the first interview talking about her mother and their estranged relationship. I did wonder if this
indicated a deeper level sadness precipitated by the vulnerability she has experienced
during cancer and childbirth. I also recognized, however, that this is a pattern typical of
how she talks, with lots of detail, tangents, and circularity in her stories. Her conclusion
appeared to be that she can no longer “stress myself out over her anymore” but instead
needs to “worry about myself” and put things into perspective.

Marie mentioned that at first she questioned why God did this to her? Raised
Catholic, she attended Catholic schools all her life, and yet she was not actively
practicing Catholicism at the time of her breast cancer. Her reaction was

I hate you God, why did you do this? …Why did he have to do this to me? Why
me, of all people—there are plenty of other people—why couldn’t he give it to
the alcoholic who sits at the bar everyday and beats his wife? You know, why was it…you question, you question everything.

But then apparently, after some time, she felt the urge to go back to church, and she
stated that her faith is actually stronger than ever before. She decided this was not God,
but rather “just how life is…we don’t know the reason for it, but he helps us get through it…”

Having a new baby under the shadow of possibly not seeing her grow up is
always in her mind. She journaled throughout her cancer experience and is recording
daily pictures of the baby as well as memories for her to have if Marie is not alive to
completely raise her. I asked her what this was like, and her reply was

It is very hard…I mean, it’s crazy, you know, I will be in the shower and I will
think, ‘when she gets married, what if I am not here, you know, or when she
graduates from college, what if I’m not here, or when she has kids, what if my
cancer has come back and I am really sick and I can’t see my grandchildren”—
yeah, I think about that stuff all of the time…I have never said that to anybody. I
mean, I just try to live every day and watch her grow every day. I want her to
remember who her mommy was.
Marie’s one-word description of having breast cancer is bittersweet. She stated that it was a very yucky experience, but that many good things have come out of it. She described a deeper faith, a closer relationship to her husband, the joy of being a mother, and wonderful demonstrations of caring and support from friends. She has also had opportunity to speak with other newly diagnosed women and help them with support and information, something she hopes to eventually do more frequently in a local cancer support center.

I Was Lucky: Olivia

Olivia is a 54 year old white female who has three sisters, two of whom have also had breast cancer within the past four years. Her oldest sister was the first to be diagnosed at the age of 52; then the second youngest was next, diagnosed one year later at 46; then Olivia at 52 the following year. The youngest sister remains cancer-free so far. The sisters have undergone genetic testing and genealogic evaluation upon learning that their maternal grandmother also had breast cancer in her 50s. Although their mother’s status is unknown (she died by suicide in her 40s), the genetic counselor thought it was highly likely that she had carried the markers for breast cancer. The BRCA tests were negative, but the genetic counselor informed them that they all had many significant markers for breast cancer and melanoma (one sister had had melanoma before breast cancer), and that they were definitely all high risk.

Until a few years ago when they moved to a major metropolis in the Midwest, Olivia had lived in the local area and worked as a police dispatcher. She was here for a family visit at the time of our first interview. Sitting outside on the deck, hearing the birds chirping, feeling the warm sunshine, she spoke freely about how it had been to go
through the same terrifying process she had just watched two sisters experience. Blonde, petite, in a summer sundress, she looked healthy and fit; she did not look as though she had undergone a bilateral mastectomy.

Her story began with over ten years of cystic breast problems and hyperplasia, four earlier biopsies, and constant watching and fears of cancer occurrence, heightened after her sisters’ diagnoses. Then two years ago, another suspicious mammogram and some questionable medical advice prompted her to seek a new specialist at a major medical center who dealt only with breast oncology. He immediately biopsied the area, then performed a lumpectomy on the left breast to take out the hyperplasia. When she returned to have her stitches removed, she received the startling recommendation to have bilateral prophylactic mastectomies.

After the lumpectomy, I thought everything was fine. So I went in to get my stitches out because I had a fairly good sized incision from that. And I about fell off the table because I went by myself and that’s when they told me that they thought I needed a mastectomy—a double mastectomy. And that was because they had really sat and looked at our profile…

After six months of researching, obtaining second and third opinions, and struggling with decisions, Olivia did consent to bilateral mastectomies. The truly amazing result was that when “the pathology report came back from that, I actually had active cancer in the right breast, which didn’t even show up on a mammogram!...so I just feel very lucky.” Her physical recovery was complicated by infections and additional enlarged lymph nodes, entailing several additional surgeries, but she was just very grateful to not have to have chemotherapy. At this point, she is recovered, but still experiencing some serious fatigue.
Olivia said that she felt great relief at the discovery of the unexpected cancer, since it lent credence to her decision to have the mastectomies. She also has recently retired from her job in a doctor’s office, in order to focus on regaining her health—“to become healthy,” and she stated that she is really enjoying life and the time to do what she wants.

Adamantly against the advice of her doctors, she chose to remain on her hormone replacement therapy and refused to take Tamoxifen or Arimidex, because she is “choosing quality of life over quantity.” She underwent a hysterectomy at 26 for uterine fibroids, and she has been on hormones since that time. Her breast cancer was not hormone positive, and she feels she is under close enough medical supervision to make the risk of negative HRT effects less than the unpleasant menopausal discomforts.

When asked her views about considering breast cancer a chronic illness, she was puzzled and acknowledged she had never thought of it that way. She said she could see that her one sister, who had had Stage III and a very bad experience with her chemotherapy treatments, would fit a chronic illness definition. But for herself, she truly believes that she is “over and done with it.” She did what she had to do, “moved on,” and was “lucky.”

I’m Proud: Riley

Riley was a referral from a respected breast surgeon. Diagnosed with breast cancer at the age of 39, she stated she had realized she might be at risk because her aunt had it; however, she was not expecting to find a lump until she was much older. Although she is negative for the BRCA 1 and 2 genes, the genetic counselor and oncologist have cautioned her she is still considered high risk for recurrence, with a 1:3 chance, due to the
aggressive nature of her original tumor. Consequently, they have advised a prophylactic
mastectomy on the other side.

Riley is married and has no children. Her large chocolate Labrador retriever, who
was at her side constantly during her chemotherapy treatments, is her baby. She is a
project manager for a land surveying company, typically working long hours with a great
deal of responsibility. She, her husband, and their dog live in a mid-sized city in an older
neighborhood. Her extended family also lives nearby, and she described them as a “large
Italian family.”

When I met Riley for the first time, I was struck by her petite, youthful, boyish
appearance. Her hair, just growing in from chemotherapy, was dark and curly. An avid
runner, she stated that her short hair was much cooler and more convenient for running.
Her dark eyes danced and smiled, and she was just a delightful person to talk to. Since
she was my first interviewee, my anxiety level was high, so I was grateful for such a
pleasant and warm person. She was open, very articulate, and talked easily about her
experiences and her feelings.

She described finding her lump:

I went on a diet. I joined Jenny Craig in May, and, well in February I went for my
gynecological exam. I have very small breasts, so it’s not like they’re dense, you
feel the bone right through it. So it’s not like, if there is a lump there she would
miss it. I was lying flat on the table, and the breasts are pretty much like a boy—
nothing. This was in February. I went on a diet in May and probably by June, I
had lost maybe ten pounds. I was lying in bed [gesturing to her abdomen and
chest] and I’m thinking, oh my gosh, I’m getting a little thinner—What the heck
is this????
Her plan is to have a prophylactic 2nd mastectomy with bilateral reconstruction at six months after completing radiation, because the thought of finding a second primary cancer “scares me to death” and her risks should be lessened by the surgery.

She stated that she felt “proud” to be a survivor; she believed that she had had the courage to do what she needed to do to get through the difficult times of recovery and treatment. She remarked that there had been times that she thought she would never be strong enough to handle chemotherapy, but she recognized that she had found that “strength within you” to “choose life” and do what she had to do. She believed that her experience of going to college in her 30s, while working a full-time and also two part-time jobs, and finishing in three years, equipped her with some of the skills to cope with chemotherapy (perseverance and goal-setting). As she talked she used metaphors such as fighting a war or climbing a mountain, and her stories were very descriptive.

Her desire was to learn to live in the moment and enjoy the now. They have been saving for a new RV. She was hoping that they could purchase it soon and enjoy it right away, rather than waiting to save more money, stating that “who knows what tomorrow holds for any of us really.”

All I Ever Wanted Was To Be A Mom: Claire

Claire is a petite engaging young woman of 33, with a pixie hair cut, dancing eyes, and a huge smile. Her joyous expression and energetic attitude belie the fact that she is currently fighting her second recurrence of metastatic breast cancer. Diagnosed four years ago, with Stage 1, no lymph node involvement, and an excellent prognosis, her recurrence in 2006 was unexpected by anyone. Treated successfully and cancer free for
several months, this present recurrence was discovered just days prior to our first interview.

As she told her story, her entire breast cancer experience is intertwined within the context of her struggle with infertility. After undergoing tests for infertility and treatment with Clomid, Claire and her husband finally conceived twins. At 28 weeks, just three weeks after her husband’s mother died of a brain tumor, Claire began labor. One of the twins was born normally, but her sister died at birth of anencephaly. With a tiny newborn in the neonatal unit for weeks, complicated by grieving the loss of the other baby, Claire became exhausted. During this time, they also moved to a different city, when her husband began a new job.

When their daughter was a toddler, Claire felt a sharp pain in her breast and found a lump. All the doctors encouraged her that breast cancer did not elicit pain, so she was not concerned about the results of the biopsy. However, when the results were positive for cancer, she was devastated. Since her husband’s sister was getting married right after Christmas, she put off her surgery until New Year’s Eve. She elected a bilateral mastectomy at that time, because she did not want to worry about recurrence, and also so that she could have bilateral reconstruction and not be “lopsided.” She mentioned she did not “want to worry about it for the rest of my life and always be feeling for a lump”; however, “little did I know that I would get it again.”

She described scrubbing her bathroom floor prior to her surgery, “I just needed to do something normal and just…you know, that’s how I coped with it I guess...” and crying, “‘I don’t want to die, I’m too young, I have a baby’, you know and I was just kind of begging God…” Claire and her husband are devout Christians involved in public
leadership within their church. She acknowledged that the loss of her baby and the breast cancer dealt a hard blow to their faith. She questioned God “why do I have to go through this?” Relieved at the pathology report of Stage I, she argued against having chemotherapy, but finally acceded to the treatment because of her age and her daughter. After completing treatment, she felt she was just going on with her life. She refused to start Tamoxifen, because they wanted to try to have more children, and her oncologist thought that was a safe decision.

Once again, they struggled with infertility, until they both just gave up exhausted. After much struggle and prayer, they decided to adopt an international child, and were overjoyed when their application was accepted and all was in order. Her recurrence occurred just after their final acceptance. They had brought their nearly two-year-old daughter home just shortly before our first interview.

When asked what her reaction to the news of recurrence was, she said it had been a relief. She had worried about it coming back, and now that it had happened, she knew what she needed to do to fight it. However, her second experience with chemotherapy was excruciating. She was very ill and unable to use her hands or feet. Fortunately, she seems to be tolerating the treatment she is currently on for this recurrence quite well, and is hopeful about the outcome.

Claire talked about the faith crisis she and her husband have been through. Because of their position in church leadership, they felt they could not be honest about their struggles, and consequently, they have not been able to share this with anyone of their faith persuasion. Claire also hesitated about seeking professional counseling help:
I was just a survivor, you know, yeah, I mean, I wanted a counselor but I was probably always afraid that there was no one who would really understand me – that could, you know, get it, you know – they hadn’t been through it so what did they know, you know. I kind of had that attitude towards it. Uhm….

However, their finances and their situation changed, and they were able to complete the adoption, and her husband is considering a vocational change out of ministry.

Claire also talked about what it really was like to go through breast cancer again:

yeah, but you know through all of that I never thought that my cancer would come back. I never gave that a second thought. I just was living my life and trying to enjoy everyday – even though, through the struggles and finally when we started….it was about at the end when my husband was really going to the counselor..

You have to fight it and just don’t think that this is just a part of my life, where before, you know, I just wanted it to be a part that was just done. I didn’t want to even really think about that any more. Where now, it’s just…Ok, you know, I’ve got to have another scan—OK. And sometimes I fight against that, you know, I get depressed or sad, you know. But I think for the most part you just kind of deal with it and I just take it a step at a time. I don’t think of it long term too much. I just think, ok we’ll just deal with today and we’ll go from there.

She openly discussed what facing her own mortality has been like. Not knowing what the future may hold, she hangs on to hope, trying to “grasp onto life even more and just enjoy every day and every moment…” She recognized that she just [doesn’t] care about the nitpicky little things, you know. I am not as uptight about it—you know, there is no need…I don’t know (laughed)…you know how people get their panties in a wad (chuckle)..and it’s like—whatever. It’s not that I don’t care about things—it’s just that some things are just not worth struggling over, you know. Definitely having gone through the 2nd time has changed me so that I value every day so much more.

Dealing with the grief of losing a child plus the sorrow of not conceiving proved to be a struggle for her, and she commented, “going through the breast cancer wasn’t as hard as losing a child.” Now she stated she felt that life was good again, and that she has covered the “long road to healing.” She also reported that her relationship with her
husband has grown stronger, and “he is really my best friend…I have him to lean on.”

Having their new little daughter has been especially sweet, and she is enjoying having a
toddler around and focusing on being home with her daughters. “All I wanted—was to be
a mom and have a few kids…”

Chapter IV Summary

The purpose of Chapter IV was to present the findings from the analysis of the
interview data. The participants showed support for the construct of change, but not the
epiphanic quantum change discussed earlier. Additionally, the stories strongly supported
three of the four research questions. The participants did not completely understand their
breast cancer experience as having a chronic illness. The following Chapter V will
discuss the themes that emerged from the data analysis, possible areas for future research,
and implications for counselors and for counselor education programs surrounding the
needs of breast cancer survivors.
CHAPTER V
CONCLUSIONS

Introduction

“My biggest fear was that I would die and I wouldn’t be able to take care of my
children…you know what? I wasn’t as prepared as I thought.” Annie

During the data analysis, two meta narratives, or overarching conceptualizations,
emerged from the data: Change and Meaning. Within the meta narratives were four major
themes which corresponded with and elucidated the meta narratives. Three major themes
were Negative Change, Chronic Illness, Posttraumatic Growth under Change, and the
fourth was Mortality under Meaning. Four additional themes were identified as part of
Negative Change: Invisible Illness, Invisible God, Lost Voices, and Lost Expectations.
Under Posttraumatic Growth were New Self Perception, New Possibilities, New
Relations with Others, New Priorities, and New Faith. The themes and the illustrating
stories from the survivor participants follow below.

Meta Narrative: Change

An underlying premise of the current research was the construct of change: did
survivors change as a result of having breast cancer? If so, what kinds of changes did
they experience, and how was that process for them? All reported that breast cancer had
in fact changed them, and they saw their lives in “before and after” terms (Calhoun &
Tedeschi, 2006; Miller, 2004). All of the women reported many kinds of change as a result of their breast cancer. However, none reported any evidence of the sudden epiphanic change resembling a dramatic watershed event such as that illustrated by quantum change theory (Miller & C’dé Baca, 2001).

The quantum type of change is still a viable construct, however, as evidenced by Mackall’s (2007) recent book. After years of sobriety, the author’s old nemesis of chemical dependency erupted into a downward spiral towards addiction following the drug-related suicide of a high school friend. In this extraordinary memoir, the author recounted the loss of faith and the deep despair of hopelessness. After a spiritual awakening that closely mirrors the quantum change experience, Mackall found sobriety and purpose in life once again (2007).

Survivors’ reports did support dramatic changes in areas such as lifestyle (Riley, Claire), values (Janis, Olivia), priorities (Marie, Annie), and relationships (Bonnie, Gretchen, Olivia). Their changes supported major themes from the literature, such as changes in relationships or priorities. Additionally, they reported both positive and negative changes. Although many changes were remarkable, with shifts in values and thinking (Olivia, Claire) (Miller, 2004), it appeared that their experiences of change have occurred via a slower process. It is possible that some were still experiencing the early stages of ruminative cognitive processing described by Calhoun and Tedeschi (2006), and that they have not had enough time yet to arrive at a level of meaning reconstruction for their cancer (Neimeyer, 2006) (Riley, Janis).

For Marie, an important change was obvious and very evident: her six-week-old baby girl. Diagnosed with breast cancer at 28 after three years of marriage, she harvested
eggs prior to chemotherapy because they wanted to start a family. Not only did she go through aggressive breast cancer treatment, but also the procedures for harvesting eggs and in vitro insemination. Not certain that she would be able to conceive after the first in vitro failed, they were surprised to conceive naturally, and the baby in the swing in the living room was the proof. Marie’s comment about having this baby was “I’m not waiting anymore for anything in my life, because I can’t take it for granted that I am always going to be here.” Describing a busy life before cancer, with both of them working full-time, and with Marie also coaching and attending graduate school, her primary theme during her interview was learning not to take anything for granted. She described spending more time with her husband, sitting and talking, and now focusing on the baby.

Riley stated she had more self-confidence after experiencing breast cancer. She described herself as previously somewhat insecure, self-effacing, and people-pleasing, and full of doubts as to whether or not she could actually go through the chemotherapy treatments. After the treatment, she stated she had gained self-confidence: “I am proud I went through this treatment. I think I handled it well.” She also stated that “I know it is not going to be like before—it will never be like it was before, but I am going to try…I’m not going to dwell on the negative.” She felt she was different at work, more confident, and different at home, with different priorities, desiring to savor life.

Major Theme: Negative Change

Consistent with the literature (Tomich & Helgeson, 2004) some of the women reported negative changes, and I tried to empathically support them as they shared examples. There were reports of negative moods and affect (Bonnie, Marie, Claire),
altered relationships (Janis, Bonnie, Olivia), and sexual difficulties (Gretchen, Riley, Claire). Bonnie mentioned disappointment, anger, and bitterness at the lack of support she received from people she thought were close friends and even her mother. Describing a lack of understanding of what she was going through, “What people want to do is they want to put band aids on things…they just don’t have a clue…friends were there to call, but not to actually do.” She stated she was still very hurt and found it painful, “The pain is still there, you know—I am just starting to heal from that.” She told a story of extended family who still expected her to be the organizer of reunions and the caregiver for their mother. She described friends who would call, saying “if you need anything, let me know” or ones who would talk about themselves and their troubles ‘”yeah, I am sick, too’ or ‘yeah, I have to work’” and admitted her anger is still unresolved.

Olivia reported how her relationship changed with the one sister who has not been diagnosed with breast cancer. This was the sister she had previously been the closest to, the youngest of the four, and this sister is the one who opened her home for our first interview while Olivia was in town for a visit. After months of agonizing over deciding to have the prophylactic mammograms, Olivia experienced a strong negative reaction from her sister:

So it was like, I had made the decision…all of the sudden I had made it and I got such a negative response from her that it just sent me totally backwards—totally, totally backwards…and it probably shouldn’t have, but it did. It made me start all over again. So I didn’t have a lot of support here—she didn’t come [after surgery], she didn’t help, she really didn’t call—it was just that she was very much against it.

The sister in question had adopted an alternative medicine viewpoint, complete with dietary changes, yoga, and meditation, and she had discussed Olivia’s case with her
homeopathic doctor. She told Olivia that her doctor believed Olivia was being “too radical” in her decisions, a comment that Olivia resented. More importantly, she was saddened about the loss of intimacy in her relationship with this sister, stating that this was now a conversation they were unable to have. “I try to just skip by it and know that that is a little bit of her personality, but it hurts, it still hurts to this day. It’s nothing she talks about.” Fearing that one day this sister is likely to be diagnosed with breast cancer, Olivia is concerned because her sister is relying on yoga and lifestyle, rather than having mammograms or breast screenings.

A few have experienced sexual difficulties, related to the chemotherapy-induced menopausal changes of vaginal dryness and lessening desire, or related to body image issues. Gretchen talked about how her relationships with men have changed and how she keeps men at a physical distance, partly because of breast discomfort, but also because she feels awkward with the skin and shape changes of her breast:

Uhm (pause)…I had relationships, you know, with men, but it changed. It was like, (chuckle) I don’t want them touching [her breast], you know—and I don’t know if they felt the same way, but sex just wasn’t the same anymore. I don’t know if it is me, but to me that was it… I still have a couple friends, but I keep them at bay…

Invisible Illness

Survivors reported experiencing the aspect of invisible illness (Charmaz, 1999b), that expectation that the breast cancer survivor is not really ill because she does not look ill. This is often the reason behind an apparent lack of physical and emotional support given to survivors. People think that once the surgery area heals, the woman is back to normal functioning, and they expect her to move on. There is a lack of recognition that the survivor continues to adjust to physical and existential changes for years (Cordova, et
al., 2001; Little, et al., 2002; Pelusi, 1998). The group of women interviewed all reported not feeling like themselves even yet.

Marie experienced this with her mother-in-law, who demonstrated disapproval that Marie was not breastfeeding their baby. Her husband defended their decision, stating “you know, she did have breast cancer—even though it doesn’t seem like she did…she has to deal with that every day, so don’t say anything to her about it.” Gretchen mentioned that “because, you know, you don’t even stay at the hospital—you come right home and I think it is easy to not realize the physical toll that it is taking,” people fail to recognize that the woman is experiencing many different aftereffects and needs support. Bonnie’s experience included an altered role attitude from family members, with “you know, it’s almost like you are not allowed to be sick.” She believed her husband had been poorly prepared for what he might expect from her during her treatment:

I don’t think that anybody ever spoke to my husband about my illness or anything, so he really just didn’t understand. He just thought I would be sick for a little bit, but that I would keep up and keep going on and so…

Her opinion was that breast cancer was not a “disease where people can actually see them as ill” and therefore, did not always see a need for help. Since Bonnie is a registered nurse educator, I did have to wonder how it was that she had not prepared her own husband for what she would experience during her recovery. I had to consider the possibility that it had been difficult even for her to accept that her role as advocate and caregiver in the family would have to change.

Bonnie seemed to resemble Janis in that respect. Janis was first diagnosed with breast cancer at the age of 61, and her second primary occurred less than a year ago when she was 80. The first cancer surgery took place while she was on spring break during her
graduate studies for a master’s in history. She had a lumpectomy without removal of any lymph nodes, and surgery was her only treatment. She returned to school at the end of break, and “it was no big deal the first time.” She kept herself busy with studies and keeping the house up to her perfectionistic standards. She also described her husband as “from a big Italian family” where the expectation was that the wife did all the housework and took care of the husband.

When Janis discovered a lump in her other breast, she expected a similar recovery process, regardless of the actual reality that she was nearly 20 years older. Even with the addition of radiation this time, she proudly announced she had taken “only two naps” during her recovery, blaming her upbringing and “work ethic—like it is sinful to watch TV during the day.” She stated that it was “better for me to do things and not think about it…” and did not consider herself as recovering, partly because she did not have a radical mastectomy but “only a partial.” It is possible to conclude that Janis did not want to give herself permission to be “ill,” either because she minimized her cancer since she did not have a radical mastectomy, or because it paled in view of her husband’s nearly fatal heart condition prior to this cancer episode.

**Invisible God**

Several mentioned that they had experienced a deepening of their faith during their survivorship trajectory (Annie, Gretchen, Gretchen), but Marie and Claire discussed openly the negative effects on their faith. Marie spoke of being angry with God about her situation. Describing herself as an avid runner with a healthy lifestyle, she could not understand why certain family members “who smoke and drink and probably have never exercised a day in their life and then, here’s me” could escape being afflicted with cancer.
Talking about her Catholic faith and educational background, she stated “when I got sick—it was kind of like you know ‘I hate you God, why did you do this?’” She stopped going to church for awhile, and questioned why the “alcoholic at the bar” or the one who “beats his wife” could avoid getting this. She stated that she wondered if it had been payback, “maybe he is paying me back for all the things I did take for granted.” It is not uncommon during an extreme crisis to believe either that God caused it (the cancer) or that he is being indifferent or punitive at not providing a satisfactory outcome (Gall & Cornblat, 2002). Marie has now come to the point where she can accept that God has “a reason for what he did and we don’t know the reason, but he helps us get through it, and you know, not to take my faith for granted anymore.”

Claire described herself as a Christian, and she and her husband are in ministry leadership within their local church. Reeling from the sudden death of her mother-in-law, her pre-term daughter’s death after their battle with infertility, and then her own diagnosis of breast cancer at 28, her questioning God is understandable. “Wow, haven’t we been through enough—we were trying to restart our life, you know, trying to get over the baby that we had lost…” Then she recalled begging God to spare her, because “I’m too young, I have a baby.” Additionally, because of their public ministry, Claire felt she could not afford to be real with her struggles, but had to present a certain appearance of strong faith. Additionally many of her peers were “passing her up” having babies, and that was also hard. She stated that she used to believe that God worked everything together, but that “that wasn’t the case in my life.” She withdrew from any kind of public ministry, and even attendance at church functions at times. She stated that she is at peace about life after death; she has not questioned that. It is just the daily living, or the process of dying
that concerns her. She also mentioned that she does not really try to find a reason for these losses: “That is cheapening what I went through in my loss to try to pin some human reasoning on it.” Instead she is just trying to be patient through the experience and accept what is.

Lost Voices

The medical model of care is based on an expert stance of the practitioner, which results in loss of agency and power for the patient. When doctors diagnose and prescribe for the patient, they ultimately rob the breast cancer patient of her ability to “name” her own distress, feelings, and future, by either over-pathologizing or minimizing what she is experiencing (Brown, 2000). Consequently, her meaning making process may be blocked. How can anybody truly know what a particular disease means for the individual who is stricken with it? The woman with breast cancer needs that “empathic witness” to come alongside her to listen to her story, hear her voice, and allow her to name her own distress (Collie & Long, 2005, p. 847) and to restore her experience of personal agency (Cihlar, 2004).

Oktay and Walter (1991) conducted a large (42 participants) qualitative study of breast cancer survivors through a lifespan development lens to create a forum for the survivors to use their voice in describing their ways of knowing about their own breast cancer. The authors based their investigation on work by Gilligan (1982) and other early writers about women’s development. They listened to women’s voices as they told their stories about their experiences, with emphasis on stories that focused on social aspects and opportunities for personal growth. It became apparent during the current interviews
that some of the participants of the present research were unable to use their voices
during the time of their breast cancer journey.

Gretchen was one who lost her voice during her breast cancer experience. First
there was the callousness of the phone call from the doctor who truly did name the
disease and claim the authority to announce a plan for surgery without engaging in any
dialogue with Gretchen: “Dr. (I forget her name) called and she said… ‘you have breast
cancer…so we will get back to you with a surgery opening.’” It is no surprise that
Gretchen forgot the doctor’s name: perhaps a quid pro quo of losing the doctor’s name in
return for losing her voice.

Then Gretchen literally lost her voice:

So I had to struggle through 3 days without saying anything to anybody because I
couldn’t say it, you know I couldn’t say it…it was awful. I just walked around
and kept saying, ‘I have breast cancer’—you don’t know how bad…So I got
through the three days, but it was hard—but I just thought it was awful...

She sat alone in her apartment for the next three days, afraid to tell her sons or a friend,
because to actually speak the name of the disease made it real.

Janis reported not talking about her breast cancer to others. The first time, she was
a much older non-traditional graduate student, and she told no one she had a lumpectomy
over spring break. They had no children, and their extended family is out of town. When
I called her to schedule the interview for the research, she told me she had not talked to
anybody about her cancer except for the friend who referred her to me for the study. She
did not tell her family until after her surgery, “because I didn’t want them running down
here…” Describing the process of going through the examinations, the biopsy, the
testing, and the surgery, she was matter-of-fact in telling what plans all the various
doctors made for her treatment, without questioning their conclusions. She mentioned that she had not even asked any questions of the at-home nurses who came for aftercare. The sense of a lost voice was very strong with Janis. Verbal expression is the avenue to creation and reinforcement of meaning (Collie & Long, 2005); hence, it was not surprising that Janis had not attributed much meaning to her experience. It was only after the initial interview for the research that Janis had actually spent any time talking about her experiences, and she stated that she really had not even thought too much about it before:

I thought a lot more about what I went through…because I have had more time to think…so I have had a lot to think about and uhh—why did this—I never thought when I was going through it, why did this happen to me, but now I am starting to.

Bonnie’s experience with losing her voice was quite poignant. I found it especially surprising that she was unable to even ask for what she needed from her own husband. She commented that no one had bothered to instruct her husband in what to expect during her recovery, and yet, especially since she had a baccalaureate degree in nursing and had worked for years in nursing education and administration, it would seem that she could have done that herself. Additionally, she was hurt and angry that no one called or came to help her out with meals or errands during her recovery. Again, it is puzzling that she was unable to ask for help, or to later even share her feelings with those people who had hurt her.

It is possible that some of Bonnie’s experience might be related to her race and culture. Although there are not many studies concerning relevant issues about breast cancer with women of diverse races and culture, some have concluded that in certain cultures, especially Asian, Latina, and African American, often there is still a shameful
taboo against discussing cancer (Ashing-Giwa, et al., 2004). Ethnic, generational, and
gender beliefs can greatly impact a survivor’s response to illness (Rolland, 1998). I also
wondered if being a member of a marginalized race, one in which breast cancer is
typically more aggressive with greater mortality, might have impacted Bonnie’s
reluctance or inability to voice what her needs were. One study about racial differences in
breast cancer (Pikler & Winterowd, 2003) found a relationship between a woman’s
healthier body image perception and her ability to appropriately express negative
emotions or to reach out to others for support. This could also have been a factor in
Bonnie’s silence.

Lost Expectations

Although some of the women (Annie, Riley, Marie) reported receiving much
support from family and friends during their recovery, others commented about not
having helpful supportive relationships. Consistent with the literature, social support is
thought to help buffer against the development of negative mood or posttraumatic stress-
like symptomology (Andrykowski & Cordova, 1998) and to enhance positive change or
interaction aids in the construction of the person’s new identity as a survivor, the
woman’s new narrative. The study by Bloom, Stewart, Chang, and Banks (2004)
demonstrated that over time in recovery, the woman’s emotional support system tended
to constrict giving her decreased support. Yet, the need for such support remains essential
for improved quality of life and ultimately for her survival. However, not every survivor
found that degree of physical and emotional support from others.
Putnam (2000) described such change in US social climate in recent years as one of disconnectedness. A downward trend away from what the author called “generalized reciprocity” (doing good for others and expecting that they will in turn do good to others later) has lately characterized American society (Putnam, 2000, p. 134). Dual income or single parent households, less free time, and more social isolation seem to be the norm of today’s lifestyles. In the past, when a neighbor or friend had a life crisis, an illness, or a death in the family, offers of food and help were abundant. Collective caring seemed to be absent in the recoveries of a few of the survivors interviewed.

Listening as Gretchen and Bonnie, both African Americans, described the lack of supportive help available for them during their recovery, I recognized a researcher bias I had held. Knowing that the literature, as well as my personal anecdotal experience, demonstrated the supportive nature of the African American church (Ashing-Giwa, et al., 2003), I had assumed that their stories would be replete with demonstrations of practical caring. Instead, Bonnie stated that she had “felt pretty alone” during her treatment and recovery. Gretchen remarked that no one had brought over any food or “came over to take me out to eat” and that had surprised her. This had been hard especially for Gretchen who lived alone, since she would have liked the companionship. She believed that breast cancer was the kind of sickness that was “more mental than physical” for her, and she was lonely. Both mentioned that church friends had commented they would be praying for them, and yet had not given practical help.

Olivia experienced disappointment with her youngest sister’s withdrawal and disapproval. They argued over Olivia’s decision to have bilateral mastectomies, because her sister was adamantly opposed to that decision. There had been so much strife that the
subject became one they could not discuss. Olivia remarked that during her recovery, this sister did not call, visit, or acknowledge Olivia’s surgery in any way. Riley reported that overall she had received support from her friends, but that one friend had been somewhat distant during the process. She described a 20 minute phone call when she told her friend about her breast cancer. The friend had spent the time talking about her own concerns, while ignoring Riley’s situation. Riley said to her “I had a breast taken off, you know, I’m sorry I didn’t tell you.” She stated that she was hurt by her friend’s insensitivity, “I guess no one really understands what you are going through.”

There were also stories of disappointment in terms of the mother-daughter relationship. Oktay and Walter (1991) described the complication that breast cancer can bring to the mother-daughter relationship. Adult daughters struggling with breast cancer felt disappointment when their mothers were not supportive enough, but they often rejected a mother’s attempts at nurturing them. Conversely, when the daughters of the women with breast cancer attempted to help, their mothers often feared loss of control. Coupled with the daughter’s own fears of her personal risk of developing breast cancer, role reversals and possible life-cycle transition issues often appeared during this time (Raveis & Pretter, 2004).

Bonnie definitely felt her mother had let her down emotionally. After being her mother’s advocate and care-taker many years earlier during her mother’s own breast cancer experience, she was disappointed that her mother was not sympathetic towards Bonnie’s situation. “I don’t think I got the support that I truly needed.” The irony is that Bonnie is still functioning as her mother’s care-taker, since her mother is elderly and frail, and Bonnie daily helps her with errands and needs. As to Bonnie’s own daughter
who was eight at the time of her diagnosis, Bonnie stated it had been quite a positive learning experience for her. Her daughter had mentioned that her daddy had “still loved mommy even though she lost all of her hair” and that her best Christmas gift had been when her mommy had her port taken out.

Annie’s mother was struggling with the effects of Alzheimer’s Dementia at the time of Annie’s breast cancer. She and her father decided not to tell her mother about her surgery. The day of her surgery her parents came for a little visit. Annie described wearing a zip-front sweat suit and makeup, “…because I didn’t want my mom to know that I had been through surgery.” Later, she expressed great longing to have her mom’s love and support, and that although she realized she needed to protect her mother’s fragile grasp on reality, “…sometimes, I just needed a mom.” Her voice quivered, and her eyes filled up with tears, and I could feel her aching for her mother’s care. It was easy to see that the roles between mother and daughter had been reversed, but Annie still yearned to be nurtured by her mother.

Marie shared that she had always had a stormy distant relationship with her mother, partly due to her mother’s history of mental illness. She spent a fair amount of time during the first interview talking about their relationship. All of the difficulties seem to have escalated since Marie had her baby. As an example of her mother’s distance, Marie shared how her mother would not even call the baby by her name, referring to her at times as a boy, or even an “it.” When she learned that she had breast cancer,

I didn’t want to tell her because it is not like she cares. So I told her and I kind of knew the reaction I was going to get would be like ‘oh, OK’…basically that was her reaction—she never talked to me the whole time.
Marie stated that “…she is just not a mom—and that was hard for me to deal with too that she didn’t care.”

I was curious about why this story had consumed such a large amount of the interview time. In following up at the second interview, Marie stated that she had changed her views of her mom, and no longer expected mothering from her, and also was comfortable remaining a bit distant. My conclusion was that there was still a wellspring of hurt and anger beneath the surface directed towards her mother. I also considered that she might have used this story to deflect the interview from something else, since I had known Marie prior to the interview. However, she did seem to be fairly open during her answers, so I tended to discount that possibility.

Her history has made Marie’s desire to be a good mother to her daughter even stronger, and she admitted that she fears thinking about the possibility that she has given breast cancer to her daughter. She is busy taking daily photos of the baby’s development and journaling to her, so that if Marie were to die, the baby would “know who her mommy was.”

Summary of Negative Change

There were similarities and differences across the case studies around the above themes of change. All the women had experienced certain kinds of losses and changes. Several reported strained relationships with loved ones during their cancer, such as Olivia with her sister and Marie and Bonnie with their mothers. Bonnie and Janis were let down by their husbands’ lack of understanding and concrete help at a vulnerable time. It appeared to me that all the women had some degree of expectation about how others would respond to their cancer illness, and were often disappointed.
It is likely that the concept of the invisible illness played a significant role in the response by others to the women undergoing cancer treatment. What is important, however, is that the women did not speak up for themselves and did not ask loved ones or friends for the help and support that they needed. I think that not only is this indicative of the disempowerment that the person with a serious illness often experiences at the hands of the medical profession, but it also describes a possible gender (female) and racial (African American) response of loss of agency in difficult situations. Or perhaps there were racial or gender influences on beliefs about health and illness, or the “appropriate ‘sick role’” (Rolland, 1998, p. 19). If they had been able to name their angst, or had a supportive counselor to help them, they might have been less dissatisfied and had more personal agency (Brown, 2000).

Marie, Bonnie, and Annie experienced difficulties with their mothers. Mothers are to nurture, but Marie’s, Bonnie’s, and Annie’s could not. Olivia’s strained relationship was a role reversal, in that she had been the surrogate mother for her sister after their mother’s death. Olivia, by nature of her cancer, was unavailable to her sister in many degrees for a period of time.

Some grew in their faith, some questioned and doubted, and one returned to God after a period of avoidance. Whether described as a faith in God, or the way an individual was raised, they all reported some kind of existential struggle to try to cope with what happened. Once again, it is sad that they were not able to talk about their struggles with friends or spiritual advisors, but instead chose to remain in silent isolation. It is all too easy to assume that women are coping well with breast cancer without actually considering the context of their lives.
Major Theme: Chronic Illness

An important task for an individual or family experiencing an illness is to arrive at some degree of meaning about the illness. Illness challenges a person’s understanding of self mastery and invulnerability. It is important to identify what a particular illness means to a specific person (Rolland, 1998). Although breast cancer is acknowledged by professionals as a chronic illness, with an episodic nature, lack of guaranteed cure, financial depletion, relational strain, and physical changes (Scott Dorsett, 1992), most of the participants did not view themselves as chronically ill. This might be a corollary to the whole idea of the invisible illness associated with breast cancer. Or it might possibly be that the early days of treatment are so fraught with survival concerns, that now that they are not undergoing active treatment, the disease is seen as less intrusive (Bloom, Steward, Johnston, & Banks, 1998).

Olivia seemed to best illustrate this paradox. When asked if she thought of herself as having a chronic illness, she actually seemed to be puzzled at first. But then she commented that her one sister who had had the most aggressive case could be considered as having a chronic illness. “…I think with her it is a chronic illness; but for some reason with myself, I don’t. I think in my mind, I am over and done with it.” She stated that she had been proactive, had caught hers very early, had not had to deal with the aftereffects of chemotherapy or radiation, and that for the most part she had really put it behind her. She simply refused to dwell on it. It seemed that for her a chronic illness would be someone who was either ill, or had lots of worries and fears. She described the same sister as believing “with every sneeze, every ache, every everything will cause her to
think that the cancer is back.” As for her, “I can’t think that way. I just think I am done
with it.”

One aspect of having a chronic illness is the financial drain on the family. At the
time of her diagnosis, Bonnie was dealing with her husband’s recent diagnosis of
diabetes. She spoke openly of the loss of income as a result of their absences from work,
coupled with the expense of the cancer treatments. Even with insurance, the co-pays
became astronomical. Her main concern was that there would be enough discretionary
money for her eight-year-old daughter’s activities and needs. Now that she has completed
her treatments, the chronicity of her husband’s diabetes seemed to be more concerning to
her over the long term than her breast cancer.

Another aspect of a chronic illness is that recognition that one’s body has
betrayed herself, and that she is no longer invulnerable (Rolland, 1998). Annie described
it as having “had a health scare, my health has betrayed me.” Gretchen remarked about
some of the physical aftereffects of her treatment, including unpleasant hot flashes. She
also noticed that she no longer had the same energy, “I could walk 3-4 miles before and
now I can do maybe 1 mile…it is a traumatic thing.” However, in terms of her view of
breast cancer, she did not consider it a chronic illness; instead, she thought it had been a
“life-altering” experience.

Claire most exemplified the chronic nature of breast cancer. She was experiencing
recurrence with metastasis of her cancer to her liver, her spine, and her lung. Metastatic
breast cancer, Stage IV, is considered incurable. Not only had she been through this once,
but it has recently recurred a second time. She was on her third round of chemotherapy
treatments. Her desire originally had been to fight breast cancer and then put it behind
her. Unfortunately that was not the case. Her comment was “it just means that you have
to fight it and just don’t think that this is just a part of my life that was done…we’ll just
deal with this and I just take it a step at a time.” Her chemotherapy treatments during her
initial recurrence caused severe hand and foot disease, and she could hardly walk or hold
even a bottle of water. She was literally incapacitated and immobile for months after the
treatment ended. Coupled with the physical changes, she also had experienced a role
reversal from being highly active and visible at church to taking a back seat. Comparing
herself to the wives of her husband’s co-workers, she stated that since having Stage IV
cancer, “I have focused completely on life and home and my family…for the most part I
am really the only one that is not involved, but I don’t feel bad about that. They don’t
have to live with what I do…”

Summary of Chronic Illness

The idea of a chronic illness seemed to be one with which the participants agreed
in theory, but they did not all believe it applied to themselves. Olivia equated chronic
illness with severe noxious treatment effects and advanced disease as her sister
experienced, but it did not apply to herself. Janis thought breast cancer resembled asthma
or pneumonia in that increasing numbers were being diagnosed, but she did not see a
parallel in her own life. Conversely, breast cancer had “been no big deal.” My conclusion
was that since they all had completed treatment and were considered cancer-free (with
the exception of Claire), chronic illness did not fit their perception of their experience of
breast cancer. Claire, however, was daily living the chronic aspect, fighting a second
recurrence of metastasis and currently experiencing treatment effects.
**Major Theme: Posttraumatic Growth**

The literature supports that for many breast cancer survivors, positive growth and psychosocial benefits appear as they negotiate the survivorship trajectory (Bellizi & Blank, 2006; Cordova, et al., 2001; Weiss, 2004). First identified by Tedeschi and Calhoun, posttraumatic growth is defined by them as “positive psychological change experienced as a result of” traumatic events (2004, p.1). The eight women who participated in the current research confirmed in varying degrees the following domains specific to the construct of posttraumatic growth.

**New Self Perception**

Calhoun and Tedeschi (2006) categorized the first domain of posttraumatic growth as including changes in self perception and the recognition of oneself as vulnerable in an unpredictable world. Riley demonstrated this self-change when she stated that she was “proud” to be a survivor, to have had the courage and strength to do what she had to do, which was to deal with the surgery and the chemotherapy. She recognized that she could have refused any of the treatment at any time, but she persevered with a positive attitude, which surprised her. She stated she felt stronger in herself, “…stronger in that if a challenge were to come my way I could take on that challenge. I’m not so insecure…I feel I am stronger.” She also stated that she knew she would never be the same, and that her life had indeed changed, but that she tries “to keep it as normal as possible…but I am going to try not to live in that fear.”

Annie used the phrase “bitter or better” to describe how she viewed her cancer’s impact on her life. She believed that the choice was hers to make, and she “vowed it would make me better.” Stating that she did not want to have cancer, “am I glad I went
through it? I think it has made me a better person. It has made me closer to God…to rely on God in your faith. Cancer stinks, but...I am a better person because of it.” She felt she had become more loving and compassionate and was a better friend to others.

Although each woman realized that cancer was unpredictable and there were no guarantees that it would not recur, Marie’s comments most clearly reflected the upheaval in worldview and assumptions discussed in Janoff-Bulman’s (1999) work, that underlying belief that the world is just, and people who are good receive benevolence and bad people receive justice.

I am an avid runner and I was always very healthy, and from all of the people in my family, I am the one who gets cancer when there are people who smoke and drink and they probably have never exercised a day in their life and then, here’s me…I hate you God, why did you do this?...why did he have to do this to me? why me of all people—why couldn’t he give this to the alcoholic who sits at the bar everyday and beats his wife?...maybe he is paying me back for all of the thing that I did take for granted, or..why would he do this to me? I think I am a good person—I tried to change my life around and I am doing good things for people— I don’t know—what was his reasoning?

New Possibilities

The second domain includes the recognition of new possibilities, new interests, or a change in life direction (Calhoun & Tedeschi, 2006). Claire made new possibilities a reality. Desiring but unable to have more children, she and her husband adopted a little girl from China. Despite a Stage IV breast cancer, Claire is committed to living life in the fullest, and for her that means being a mom. She has learned how to cope with the demands of young children while coping with the noxious effects of chemotherapy.

Gretchen stated she is planning to move away from the small town where she has lived all her life to a major city close to her son. She stated that although she was sad to leave, she was eager to move and excited about the possibilities for new friends and
perhaps even a new romantic relationship. Olivia stated that she was learning to do the things she had always put off. She remarked that she golfed because her husband liked it, and she did it to please him. However, she now wanted to do things that pleased her. She has begun taking painting lessons and cake decorating. Retirement has opened many new possibilities for her to consider.

*New Relations with Others*

New relationships and deeper connections often follow trauma or crisis. Developing greater closeness and compassion may become the basis for altruism or service according to Calhoun & Tedeschi (2006). Nearly all the women described stronger, closer, and better relationships with loved ones, as well as times of reaching out to others. Annie mentioned that she and her husband were much closer today and their relationship is much stronger. Going through the difficulty of cancer actually drew them together. Marie, too, reported that she and her husband had become much closer and talked much more. They each work full-time, and Marie also coaches and is a graduate student. During the summer, she manages a local swimming pool, while her husband plays softball and golf. They had been married only three years when she discovered her lump, and she said her husband had a harder time dealing with it than she had. She described him as a person “who keeps everything inside and he tries not to show me that he is upset.” After going for counseling at a local cancer center, they have been working very hard at talking and listening to each other. Now, he has “just kind of stepped it up a little” and helps out more, and spends more time with her and the baby. “We took our vows, you know, in sickness or in health…and we just don’t take each other for granted.”
Marie has also been working at becoming closer with her sister, another strained difficult relationship. Although “we are still not very close” she did find that her sister was supportive emotionally through the cancer experience. She described a close-knit group of friends who had become very much like family during this time. A few of them would even come and just sit with her when her husband was working so that she would not be alone. “…all of our relationships with our friends grew so much better…closer, and you just realized who was there to help you.” She speculated that her getting breast cancer at such a young age had been an “eye opener” to their friends, a realization that these kinds of things happen. Claire described a deepened relationship with her husband that has grown stronger, and “he is really my best friend…I have him to lean on.” Going through the numerous losses they have experienced has been difficult, but they are supporting each other. Also, dealing with the sexual changes of chemotherapy-induced menopause has added a stressor to their relationship, but “he has just been wonderful.” She also described becoming closer to a cousin similar in age who is also a breast cancer survivor. They have much in common, and although they live a distance from each other, they make trips together and talk frequently.

In terms of altruism and reaching out to others, several shared dreams of “giving back.” Olivia mentioned that she has a desire to work with the homeless and plans to start volunteering at a local soup kitchen. Marie hopes to volunteer at the cancer center when she finishes grad school. Additionally, she has been available to talk with younger women who receive a breast cancer diagnosis. Annie is very involved with Relay for Life, captaining a team each year. She also gives presentations about breast cancer at the neighborhood schools. She hopes to volunteer at the hospital and “hold the AIDS babies”
as part of her purpose in life. Many opportunities to help other women newly diagnosed with breast cancer have come to her; for example, the story about dropping off a “hope and pray necklace” for a fellow teacher whom she did not even know on the day of the woman’s first chemotherapy treatment. She has a prayer list of 25 women survivors for whom she prays daily, many of whom she has never met. Finally, Riley would like to become involved with the local American Cancer Society as a volunteer after she recovers from her second mastectomy and reconstructive surgery.

New Priorities

The fourth domain of posttraumatic growth entails discovering what one believes is important in life and having a greater appreciation for intangibles (Calhoun & Tedeschi, 2006). This was unanimously addressed by the participants. Two have taken early retirement from good jobs. Olivia quit working to reduce stress and to have time to spend with her grandchildren and to do the things she felt were important. Bonnie retired to have more time to spend with her pre-adolescent daughter, even though it meant a lowered discretionary income. “I guess those sorts of things have changed—where before it was maybe paying my house off…now it is just to be there for [her], to be here.” Riley stated she was encouraging her husband to buy that RV they had been saving for, even if it meant going into debt. The RV symbolized for her an opportunity to spend relaxing quality time with him and also with their families, which she considered a high priority. She also described no longer being such a “workaholic…to the extent I was.” She stated she wanted to take time to be with her husband, her dog, and her friends, and she would re-arrange her schedule to allow for that. They all mentioned “not sweating the small
stuff,” (Annie) and “learning to take one day/one moment at a time,” and learning to live “in the moment” (Riley).

Annie stated it so well:

Right away, one of the things that happened is all of the little junk fell away—your main priorities come into focus so clearly. I’ll just give you a little example of that. I have always wanted to put on an addition out here...it was very expensive, so we put it off and put it off. [my friend] said ‘hey you could get your addition now’ and I said ‘you know I don’t even want it. I don’t want it. I have my husband and my kids and we are here and we have everything we need.’ All of the little things fall away.

All those little things that seemed so, so important have gone away And you realize that each day is a gift, you know. I go out in my garden in the morning and I think, I am so lucky—look, I am out here and the birds are chirping, the flowers are growing...Each holiday is a little bit sweeter because in the back of my mind I think ‘I don’t know what this year is going to bring.’

*New Faith*

Existential change is the final domain. In the US, it often manifests as a change in religious faith or increased spirituality. Making sense of what happened and searching for meaning or purpose in life are the tasks of this domain (Calhoun & Tedeschi, 2006). Annie talked openly about her strong evangelical Christian faith. She had people praying for her from the time of her discovery of her lump onward.

I mean, I have been a Christian for a long, long time and I have really never understood what it meant to be prayed for and feel the power of prayer, I mean physically feel the power of prayer...before surgery—I felt this calm come over me that was not medically related...I know I am being prayed for, I felt so protected.

Going through the cancer has made her closer to God, “I truly understand what it means to give up control to a higher power and to rely on God in your faith.” Relying on God, reading the Bible daily, and having an active prayer time especially for women with breast cancer are all manifestations of the newer vitality of faith she experienced.
Bonnie, Marie, and Gretchen all talked about how they had experienced a renewal or strengthening of faith during their cancer journeys. Marie went through the emotions of anger towards God, left her church for a time, and then returned to worship in a deeper way. When asked what made her return, she did not really know. “…you question, you question everything…I think I just came to grips with it—that he doesn’t hate you…he has a reason for what he did and we don’t know the reason, but he helps us get through it.” Rather than continuing to blame God, she chose to believe in his help to get through her cancer, and stated that she is now actively involved in her church.

Bonnie and Gretchen are both members of African American churches and have experienced disappointment with the lack of care from other members during their cancer. Both described a more inward faith that had grown stronger during their ordeal. Bonnie referred to her “prayer closet,” a time of solitude where she prayed and meditated and found comfort, strength, and “confidence that things would be okay.” Gretchen felt that her faith was “what brought me through.” She described the three days in her apartment alone when she first received the biopsy results: “If I hadn’t sat and read the Bible for three days, I don’t know what I would have done.” She commented that she had never made a practice of reading the Bible regularly, and now she reads a couple of chapters daily. When asked if she ever questioned God why she had cancer, she laughed and told a story about her grandfather, the preacher. “A long time ago he said, ‘you can’t say, ‘why me’, because God will only say, why not you?’ So I knew God would say ‘Why not?’”

Claire described her faith crisis as related to the loss and grief over their baby’s death coupled with her breast cancer. She talked about begging God, “I don’t want to die,
I’m too young, I have a baby” and after the surgery, “why did I have to go through this?”

Her difficulties were complicated by not having anyone else to talk to, a situation made worse by her public role in the church, and her reluctance to share how she was truly struggling for fear of being judged by others.

I think there were times when I really could have used someone to talk to and we always talked about how I need to…Oh I should get a counselor, but I just never did it, you know. And it was hard because you had to …like with being [in ministry] you have to live a certain way, you know…

After time, Claire has chosen to believe that God is not “doing” these bad things to them, but “bad things happen in this world, and you know, we are by-products of that.” But she honestly described a dry spirituality, fears of being misunderstood by parishioners, and tremendous aching losses. Additionally, she experienced fears about her husband’s near “emotional breakdown” and his subsequent plans to change vocation.

Time has helped; so has the arrival of their new daughter from China. They have moved farther away from the church instead of living just across the street, and Claire has taken a back seat to focus on raising their daughters. She remarked that she still questions “a little bit” about “why do I have to go through this?”

Summary of Posttraumatic Growth

Consistent with the posttraumatic growth literature, the participants demonstrated areas of positive growth in their lives. Reappraisals of what was important, renewed spirituality, increased sense of purpose, and a desire for altruism were confirmed by the survivors’ stories of change. Posttraumatic growth is a construct that has been heavily supported by research in several venues, and although it is in its infancy in studies of breast cancer survivors (Bellizzi & Blank, 2006), it appears that the current research adds
support to the construct in the lives of the participants. Additionally the participants (especially Marie, Riley, Bonnie) gave support to that shattering of their assumptive worldview that accompanies traumatic life events (Janoff-Bulman, 1999).

Meta Narrative: Meaning

Overall, meaning is as individual as the various types of breast cancer represented in the research, and as varied as the personalities of the women who participated. All were impacted to varying degrees, and many of the meanings have been discussed in the preceding sections. Meaning includes benefit finding (Tennen & Affleck, 1999), enhanced positive growth after surviving a traumatic event (Pelusi, 1997), and personal discovery of new life after facing death (Moch, 1995). In the women’s stories we hear some of the meaning making they have undergone as they talked about and thought about their personal experience (Schwind, 2003).

I questioned each participant about what meaning they had made of their breast cancer experience. After the shattering of their “safe” worlds and the chaotic upheaval of their diagnosis and treatment, I was curious what their survivorship identity meant to them. Three of them referred to a loss of innocence, which seemed to be an aspect of global meaning, or that fundamental order and purpose in life contained in the belief that life makes some degree of sense (Collie & Long, 2005; Schoen & Nicholas, 2004).

Annie referred to the innocence of the state of trust that children have, until they become adults jaded by the hard things of life. Riley stated she refused to “dwell on what I have lost” but recognized that she had an innocence that is now gone, “my experience was a bit innocence-stealing” in that the bad things had really happened to her. Her psychiatrist even noted and commented that she appeared to be more serious and without
her characteristic sense of innocence. She was struggling to make sense of what had happened to her and to adjust to the feelings of depression that had surfaced after her treatments ended.

Claire’s comment about loss of innocence was “it’s like there is just not the same innocence that you used to have in your faith. You know, it used to be, God works everything together—well, that wasn’t the case in my life.” When at the second interview I questioned what she meant by that, she told a story:

We had a wedding a couple of Saturdays ago at a church and I took [daughter] into the nursery and there was no one else in there—just me and her. There was this big board where everybody just had their names up there if they were expecting and when they were having a baby…I look at that and I think, ohhh, I hope they know what they have in that they just are living a nice little life…they can just pop out the children…but to me it’s like that was always the life that you dreamed about when you were a little girl…no problems, and no illness, and I look at that and I think…I hope they are thankful …but yet it leaves me with a little bit of ‘why do I have to go through this’ you know.

Claire defined innocence as not “always hav[ing] to think about what is the next bad thing that is going to come down the path…”

Situational meaning is that intersection between what is happening in the person’s environment and her life at any given time; for example, breast cancer. Any interview with the participants is a cross-sectional “slice” of her life at that specific moment (Shapiro, et al., 1997). For Riley, breast cancer meant that she learned she was strong, able to do what she needed to do. She used metaphors of battle, and that she had “been in the trenches” but had been a good “soldier” and had “won the battle.” For Janis, it meant that she refused to become a burden to anyone, that she would clear out her household accumulation of “junk” and not leave it for family to sort after her death, and that she
would continue to “cook and clean” for her husband, in spite of breast cancer. It seemed as though she refused to really acknowledge the presence of breast cancer in her life.

Olivia believed that she had been “lucky,” especially in comparison to her one sister who suffered from more invasive disease and toxic aftereffects of chemotherapy. She accepted breast cancer as something in her genetics, but she truly believed that she was over and done with it. For her breast cancer is a genetic disease that she has beaten. The primary meaning is that she decided to spend no time asking “why” but to focus on time with family and time to do things she enjoyed.

As we talked during the interviews, it is hopeful and likely that the women began to construct new stories about their breast cancer, via the social constructivist nature of the relationship (Niemeyer, 2004, 2006). As mentioned above, that process had much power in the narrative of Janis, a woman who had not really thought much or talked about her cancer experiences, one going back 20 years ago. She started experiencing feelings of sadness and possibly depression “because I have had more time to think” and that she had “thought a lot more about what I went through.” For Olivia, perhaps a new story of a new understanding between her and her youngest sister will commence from her interviews. After our discussion, Olivia began to consider that some of her sister’s animosity might result from her role as the surrogate mother after their mother’s death by suicide when the sister was only 15. Olivia remarked that she had never before considered that this sister might be scared of losing her “other mother” and was therefore handling those fears by anger.
Summary of Meaning

As people experience specific events in their lives, it is characteristic that they attempt to understand things that happen. The participants did try to figure out what had happened to them during their breast cancer. A few stated categorically that they did not question why it had occurred in their lives (Olivia, Gretchen). Instead, their focus was on what to do next or what to expect might happen next. Gretchen even stated she was “waiting for the next shoe to drop,” as though her fears were still strong. Part of the meaning making was telling their stories, looking at their experience of breast cancer within the context of their lives. Adapting to the myriad changes and new sense of self was part of their growth. The women attributed varied subjective significance to what they experienced in their specific instances; for example, child rearing, career changes, and altered relationships. In analyzing the data, my conclusion is that for some of them (Janis, Olivia) there has not been that degree of cognitive processing or rumination (Calhoun & Tedeschi, 2006) necessary to really construct meaning for their breast cancer. This could be related to a refusal to think about what happened, or a lack of receptive audience to hear their stories.

Major Theme: Mortality

Part of the meaning making of any life-threatening illness such as breast cancer involves taking a look at the possibility of dying. All of the participants had considered their own mortality in some form during the recovery process. Janis stated two concerns: returning to attending church and cleaning out her accumulation of china, crystal, and paper “junk.” She mentioned that they had not joined a new parish since moving two years ago, and that she was feeling a strong urge to go back to church. Additionally, she
had begun to clear out, sort, and pare down, because she felt strongly that she did not want their nieces and nephews having to clean up her stuff after her death.

Marie’s consideration of dying was what it would mean for her infant daughter: would she grow up knowing who her mommy was? For all of the women with children at home, what might happen to their children was heavy on their hearts. Annie talked about her daughter, and wondered if her husband would be able to help pick out a dress for the prom? She had already joked with her friend that she knew her husband would not cook, so would she please help out with some homemade meals? For Claire, the possibility of dying before seeing her daughters raised is very real. Having already had two recurrences and being currently treated with her third round of chemotherapy, she was hanging on to hope but realistic about the possibilities. She mentioned that she did not “think of it long term too much. I just think, OK, we’ll just deal with today and we’ll go from there.”

Since she is tolerating this round of chemotherapy well, it is not nearly the hardship as during the first recurrence when she was extremely ill. She commented

You know, I think you are always like, when you first get the diagnosis and especially with the recurrence, you really think it is the valley of the shadow of death, you know and…it does [sound so final], I mean, like—I mean immediately I just started talking with my husband about what I wanted at my funeral—that is just where your mind goes, you know…you just really never know if it is going to completely go away, you are always wondering and worrying.

She remarked that her husband did not want to think about her death, but to just live in the now. However, she was the one who had “to go into that chemotherapy room every week and sit there with all of the other people, so I face it every week.” She stated she was beginning to “more and more accept it” while trying to focus on what she could do
and “just fight. You know, I will do everything and anything I can to live as long as possible.”

Claire stated that it had been almost a relief when the first recurrence happened, because the fear was gone, and she knew what had to be done. However, for the rest of the women, fear of recurrence was a big part of their survivorship, and many mentioned the anxiety of going in for the regular mammograms and other appointments. It was almost as if they could somehow avoid thinking about recurrence until an appointment arrived, when the fears and emotions were triggered. For Bonnie, that fear became real. She discovered a lump in the other breast just before our second interview. She handed me a note with the information on it so that her daughter who was home would not hear about this unless there was a reason to be concerned.

Due to the aggressive nature of Riley’s cancer, she stated that she believed she would not live a long time. Even opting to have the prophylactic second side mastectomy, she knew her odds were not the best. She admitted to being scared at the thought of recurrence, but that she tried not to think about negative thoughts too much. Her belief at present is that she would choose quality of life over length, and she mentioned that she would likely not agree to extensive treatment if it meant “life would pretty much suck.” Not afraid of death, she did state she was afraid of the process of dying if it would be painful, and it “breaks my heart to think of my husband losing me, or my parents, but it doesn’t scare me.”

Annie stated she is not convinced she has totally resolved the issue of her death. She admitted that she had sought solace and answers from her faith, and that she thought
she was less afraid of dying than of leaving her children. However, she then shared that she had been afraid of dying since childhood.

I was probably about 12—and I was lying in bed, and you know how you start thinking about something that is just really hard to grasp...I remember the first time I thought “someday I am going to die” and it scared me and I sat up in bed and I remember just yelling for my mom. Then when you are in your teens and 20’s you have that whole immortal thing going...I remember when I had my children my biggest fear was that I would die and I wouldn’t be able to take care of them...I had to face that, you know, smack—face to face—when I had the cancer diagnosis. That was a very scary thing for me...here I was, and I have been a Christian for a long time, and I know it is a better place, but that is still hard...you know what? I wasn’t as prepared as I thought.

Summary of Mortality

For most people, facing one’s own death is difficult. Regardless of faith tradition or spirituality, it is hard to comprehend not living or being in one’s physical life any longer. For the women with children, it was especially difficult to consider not being here to celebrate their children’s milestones of development and to have the additional worries of how their children would adjust to their mother’s absence. For all of them, they had looked death in the eye during the time of their diagnosis, but most had pushed the thoughts of dying aside as they became farther away from diagnosis and active treatment. Claire was the only one who had had a recurrence, and for her death may have seemed more real. However, with good response to her chemotherapy, she too was focusing on hope and planning to fight the cancer. They all had to some degree faced the unknown of death, and Riley and Claire confessed to concerns about the process of dying. Annie said it so well, “I wasn’t as prepared as I thought.”
Implications for Counseling

Miller and Crabtree (2000) stated that the purpose of research was to inform clinical practice in order to improve the person’s life. While listening to the stories of the survivors, I was struck by how insightful their stories of their breast cancer experience were, and by how professional counselors could have helped these women. As described in the previous chapters, breast cancer has been heavily researched in the areas of prevention and the early stages of diagnosis and treatment (Ganz, et al., 2004; Helgeson, et al., 2004); however, there is a paucity of research on the long term survivorship trajectory (Pelusi, 1997). Further, so much of the breast cancer research has focused on physical aspects from a medical model lens without addressing the stories of the survivors’ lived experiences (see Oktay & Walter, 1991, for an exception). As I continued to listen and analyze, I identified three areas in which counselors might use the current research to advocate for the survivor: social support, education, and agency.

Social Support

Listening to the stories, I was struck by how the survivors described experiences closely resembling posttraumatic stress-like symptoms. Intrusive sensory experiences, such as recalling the smell of burnt flesh after radiation burns or the taste of a popsicle after chemotherapy, or intrusive unbidden thoughts after glancing at the mirror following a shower, were common experiences. The physical assault on the integrity of her body throughout surgery and adjuvant treatments coupled with the fear of losing one’s life can and did provoke posttraumatic stress-like symptoms.

Given that social support is considered to be a buffer against the development or the exacerbation of posttraumatic stress, a possible strategy for prevention would be to
facilitate the survivor’s access to supportive networks. For some, group interventions would be helpful. Locally there are several breast centers or cancer centers that do provide support groups for women with breast cancer, and group therapy is empirically supported as an efficacious intervention for breast cancer survivors (Lechner & Antoni, 2004; Spira & Reed, 2003). Claire and Marie both commented that they did not like going to support groups, however, but preferred the online support of networks such as Young Survivors’ Coalition. Perhaps this is generational preference of younger survivors, or perhaps it is a matter of inconvenience for young mothers to arrange childcare to attend a group.

For many of the participants, some means of obtaining social support would have been advantageous. They could have used meals, transportation, child care, and many other concrete helps. Counselors need to consider how they might advocate for social support, not only with the survivors and their families, but with the greater community. Perhaps a series of public workshops during October, breast cancer awareness month, might help at least raise consciousness on the part of other people.

Oktay & Walters (1991) described the disparity between what the professional literature suggested and what the survivors themselves were saying they needed. Women interviewed in their study focused much more strongly on the social aspects of their illness experience, not the physical or even the psychological. We as counselors have done the survivor a disservice if we have not at least heard her story and attended to what she thought was important. If Putnam’s (2000) research on the lessening of community in the United States is accurate, then change on a broader scope is necessary. Since people are less likely to reach out to others in need, there needs to be some kind of public forum
to communicate that survivors need help. This might be an opportunity for faith communities to help out possibly.

*Education*

Education is another important role for the professional counselor to assume, and not only for the woman who is diagnosed with breast cancer, but for her family, and also for the larger community. The woman who is diagnosed with breast cancer needs to be alerted to the possibility of posttraumatic stress-like symptoms, and taught not only what to look for, but given suggestions for helpful things she could do. For example, she could warn friends and family ahead of time what to expect and of the kinds of help she would appreciate. A counselor could also discuss with the woman what illness might mean to her, within the aspects of the invisibility and chronicity of breast cancer.

The medical team is usually thorough in postoperative education about physical care. It would be ideal if a counselor could also have time with the survivor early in her recovery to educate her and her loved ones about the emotional and psychosocial aspects. Timing would need to be considered, because some degree of shock often occurs during the rapid course of the early days from biopsy to surgery. However, being able to process that path with a mental health professional might lessen some of the shock and enhance future adjustment. Claire illustrated this when she remarked she had not sought counseling because of the belief that a counselor would not be helpful unless they had gone through breast cancer. Therefore, educating the public about counseling as a profession is vitally important.

It would also be helpful if information booklets regarding what to expect emotionally were as readily accessible to women as ones regarding the physical findings.
Physicians’ offices and breast health centers would be logical locations for displaying some of this information. Additionally women need information about what an invisible illness is and how people may not consider them ill. Whether or not the current participant survivors considered themselves as having a chronic illness, the fact remains that breast cancer meets criteria for a chronic illness. Education about the waxing and waning of emotional distress over appointments, about the role reversals and the relational upheavals in the family could be very beneficial to the woman and her loved ones. Help from a counselor in identifying familial attitudes towards obtaining help and towards the appearance of needing assistance might be a useful service.

Agency

A catastrophic illness is a very disempowering experience for most individuals, especially women. Socialized that the doctor knows best, it can be difficult to question recommendations, unless the particular physician is collaborative in style or the woman has the inner strength to do so. A partner, friend, or other family member could step in and aid in questioning or gathering additional information to help in the woman’s decision making process. A counselor could help empower the survivor by listening and aligning with her to help identify what she needs. Unless the woman has an already established relationship with her own counselor, it is unlikely that she would think about seeking counseling at first. However, a counselor is not typically part of the initial therapeutic team when breast cancer is the diagnosis. Part of that is the lack of understanding on the part of the public about what counselors do. Historically, within the medical system, the social worker or the psychiatric nurse is the most likely person available to help in provision of social or psychological information to the woman.
Both are highly trained professionals, but they are more likely to utilize a medical model approach rather than a holistic developmental approach that will foster the woman’s experience of personal agency.

Counselors are equipped to practice from a biopsychosocialspiritual model and to interface with medical practitioners to help women with breast cancer. Conceptualizing the woman from a growth-oriented, person-centered holistic lens would strengthen the opportunity for the survivor to tell her story. The current study has contributed to the field by expanding the knowledge base for counselors to understand the lived experience of breast cancer survivors and to help them apply that understanding and knowledge to practice. Able to validate the survivor’s story, the counselor can help facilitate healing and positive growth for the woman with breast cancer.

Future Research

Several possibilities for future research seemed to emerge from the current study. First, continued research into survivors’ lived experiences will be important, as the few studies there are have barely begun to understand their needs. Research into survivorship and survivors’ needs is a burgeoning area within the oncological medical research at the present time. As the number of cancer survivors increases, especially breast cancer survivors in particular, medical researchers are recognizing the need for research in this area. The spouses or partners of the survivors, as well as any children, should also be considered in future research, as they are currently underrepresented in studies. Given that the current research focused on largely middle class participants, it would be important to investigate similar questions in women from non-middle class groups with less advantageous access to medical care.
Ideally, longitudinal studies would be important, as it is likely that the current survivors were still too recent in their journeys for some of the cognitive reappraisals and meaning making to be as pertinent as they might have been later on. Since change is often a slower, more continuous process, it would be helpful to re-interview these participants further along on their trajectory. Also, since the literature is replete with resources for early stages of breast cancer, longitudinal research would add to the potential for resources for the survivors who are past the five year mark with different needs.

Another especially valuable area for future research would be the aspect of mortality and how it changes a survivor’s life, as well as how time impacts that viewpoint. It is likely that the farther away from the initial diagnosis the woman is, the less important the idea of her mortality becomes, unless variables such as age or other illness influence her. Once again, given the changing demographics, and the reluctance of baby boomers to age, it would be valuable to hear what helps or hinders in facing one’s mortality.

Future study could also consider the arena of faith and spirituality, and what changes occur and how women adapt or adjust to their illness in respect to their faith. Consistent with the literature on posttraumatic growth, existential concerns are part of the final domain, often expressed as deepening interest in spirituality. Further investigation into just what changes in spirituality during a life crisis would give insight as to how to best support individuals experiencing such crisis. Also valuable would be a consideration of those survivors who have been wounded and disappointed by their faith community’s lack of caring or who are angry with God for allowing this to happen to them.
With the aging demographics of the United States in particular, coupled with advancements in medical care, the incidence of chronic illness will continue to increase. More research is needed into what kinds of daily experiences impact individuals and families with chronic illness, what their needs are, and further, how breast cancer survivors relate to chronicity. Counselor education programs need to consider curricular additions in the domains of chronic illness and long-term survivorship issues. Additionally, counselors working with such clients need to be out in the professional arena conducting workshops and trainings for other clinicians.

Unfortunately, with the reality of managed health care demands on the time constraints of counseling practitioners, it is not feasible for most clinicians to do much research, and many, in fact, are not interested. Moreover, the research that is likely to be funded will be from a scientifically evidenced-based statistical model rather than the qualitative model. Miller and Crabtree described the need to “trouble the waters and seek change [italics present] within the clinical research world itself” (2005, p. 609), in order to elicit the recognition of a need to look at understandings of clinicians about their patients. Their recommendation was for qualitative and multiparadigmatic methods to be used in clinical research so as to identify and tell the stories of the individuals. Using the recent “No Child Left Behind” educational act as an example, they categorized the current research policymakers’ funding agenda as evidence-based, outcome driven randomized designs that lend to generalizability (Miller & Crabtree, 2005).

As an alternative, it is essential that clinical research in counseling be methodologically sound, while still keeping the richness of the “missing evidence” of the people’s experiences, contexts, and power (Miller & Crabtree, 2005, p.610). Already
occurring in education and sociology, counseling’s humanistic view of the importance of
the person naturally lends itself to this type of research. And yet it is often difficult for
qualitative counseling researchers to have their results accepted by journals for
publication. As I reviewed the literature, many of the current journal articles are from the
oncology arena. I had to wonder why journals such as *Journal of Counseling and
Development* are underrepresented in my literature search on breast cancer survivors.
Perhaps it is time for “troubling the waters” (Miller & Crabtree, 2005, p.609) in
researching breast cancer survivors’ lived experiences in order to hear their stories. We
counselors need to hear their answers to “so what?” and “then what happened?” to make
sound and informed clinical decisions and provide that empathic care they deserve.

Chapter V Summary

The current research investigation of the lived experiences of breast cancer
survivors considered their stories about their cancer diagnosis and treatment and how
they changed during the time following. They openly shared their vulnerabilities, their
tears, and their joys with me during our short time together. I heard stories of empathic
medical practitioners, supportive spouses and friends, and sadly I also heard stories of
less than compassionate or less than supportive others in their lives. I laughed at a story
about an entertainer’s breast being exposed on national television the weekend Annie
awaited her biopsy results, and I cried with Claire as she recounted her losses of her baby
and her breasts.

Although the study officially was about the participants, I discovered that I also
was growing and changing as I interacted with them and their stories. I, too, discovered a
new self identity within the interactional nature of the interviews, as I became not only a
researcher, but one who was also a breast cancer survivor within the larger community of other survivors. I felt a sisterhood with the women who participated, that common yet unique bond of similar but different stories. At first, I felt I needed to resist this subjective response, putting on my researcher stance. But then I returned to the philosophy of the research, and confident in the process of subjective knowing, I allowed their stories of change and meaning to work in my life.

I had to re-examine what my breast cancer journey meant to me. I had to re-live my relationship with my mother who was critically ill at the time of my diagnosis and recognize I had missed her mothering in my own time of crisis. And I admitted my fears for my daughter and her daughters, that they might one day inherit this disease from me. I felt blessed that I had a medical team that was collaborative, and that I had enough power and agency to make my own medical decisions and to ask for the help I needed. I gratefully acknowledged my family and friends who were that supportive shield for me at that time.

I had to look at my own faith, my trust in God, my fear of dying, and examine my own beliefs about what death meant to me. And in the process, I learned about life—that sweet gift of time to love and to grow. I am grateful for having the privilege of touching the lives of the participants through this research. More importantly, I feel blessed at the privilege of having had their lives touch me.
REFERENCES


APPENDICES
APPENDIX A

HUMAN SUBJECTS APPROVAL FROM THE UNIVERSITY OF AKRON

April 21, 2007

Claudia Sader-Gerhardt
3835 Greentree Road
Stow, Ohio 44224

Mrs. Sader-Gerhardt:

Your protocol entitled “And Then What Happened: The Lived Experiences of Breast Cancer Survivors and Their Stories of Charge and Meaning” was determined to be exempt from IRB review on April 20, 2007. The IRB application number assigned to this project is 2007/0416. The protocol represents minimal risk to subjects and matches the following federal category for exemption:

☐ Exemption 1 - Research conducted in established or commonly accepted educational settings, involving normal educational practices.
☐ Exemption 2 - Research involving the use of educational tests, survey procedures, interview procedures, or observation of public behavior.
☐ Exemption 3 - Research involving the use of educational tests, survey procedures, interview procedures, or observation of public behavior not exempt under category 2, but subjects are elected or appointed public officials or candidates for public office.
☐ Exemption 4 - Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens.
☐ Exemption 5 - Research and demonstration projects conducted by or subject to the approval of department or agency heads, and which are designed to study, evaluate, or otherwise examine public programs or benefits.
☐ Exemption 6 - Taste and food quality evaluation and consumer acceptance studies.

Annual continuation applications are not required for exempt projects. If you make changes to the study’s design or procedures that increase the risk to subjects or include activities that do not fall within the approved exemption category, please contact the IRB to discuss whether or not a new application must be submitted. Any such changes or modifications must be reviewed and approved by the IRB prior to implementation.

Please retain this letter for your files. If the research is being conducted for a master’s thesis or doctoral dissertation, the student must file a copy of this letter with the thesis or dissertation.

Sincerely,

Sharon McWhorter
Interim Director

[Signature]

☑ Approved consent form attached

Cc: Cynthia Reynolds, Advisor
    Rosalie Hall, IRB Chair

The University of Akron is an Equal Opportunity and Employment Institution
APPENDIX B

INFORMED CONSENT TO ACT AS A RESEARCH PARTICIPANT

Title of Study: “And Then What Happened?”: The Lived Experiences of Breast Cancer Survivors and Their Stories of change and Meaning

Introduction: You are invited to participate in a research project being conducted by Claudia Sadler-Gerhardt, a doctoral student in the Department of Counseling at The University of Akron, under the supervision of Dr. Cynthia Reynolds, Dissertation Advisor, Department of Counseling, The University of Akron.

Purpose: The purpose of the study is to investigate the lived experience of women who are breast cancer survivors who have completed their treatment, and how their lives have been impacted by breast cancer. There will be approximately 6-10 women participating in the study.

Procedures: The participants will be asked to complete a short demographic survey and to participate in two interviews of approximately 1 ½ - 2 hours at an interval of 2-4 weeks. The interviews will be audio-taped at the time. There may be a follow-up post interview phone call for clarification if necessary.

Exclusion: Women who are currently in active initial treatment for breast cancer or women who are beyond 5 years post treatment will be excluded from the study.

Risks and Discomforts: The risks of participation will be minimal. Talking about such personal issues as coping with the recovery from breast cancer may contribute to some mild feelings of distress or discomfort in some individuals. The interviews will be conducted in private, safe environments chosen by the participants to enhance comfort. Should a participant experience distress, she may discuss this with the researcher, a Professional Counselor and Registered Nurse, for brief assistance, or she may be referred to her own mental health provider if she has one. Every participant will be given a referral list of community cancer support groups and mental health providers that she may access. Additionally, the interview can be stopped or discontinued at the discretion of the researcher.

Benefits: The benefits to you for participating in this study may be the possibility of receiving comfort or encouragement from the opportunity to talk about the experience of living with breast cancer with a supportive listener. There may be opportunity for
discovery of personal growth or self awareness. However, you may receive no benefit from participating in this study.

**Payments to Participants:** Each participant will receive a $15 gift certificate at the completion of the 2nd interview.

**Right to Refuse or Withdraw:** Participation in this research is voluntary. Refusal to participate or withdrawal from the study at any time will involve no penalty or loss to the participant.

**Confidential Data Collection:** The audio-tape recordings and the transcriptions of the interviews will be kept in a secure location. Only the research team will have access to such data. Participants will select a pseudonym for the actual interviews. Any other identifying information will be kept confidential. Participants will not be individually identified in any publication or presentation of the research results. Your signed consent form will be kept separate from your data, and nobody will be able to link your responses to you.

**Confidentiality of Records:** All questionnaires, tape recordings, and transcripts will be securely stored in a locked file owned by the researcher. The tape recordings with pseudonyms will be accessible only to the researcher, the transcriber, and the research team. The transcriptions will be accessible to the research team only after any possible identifying information has been deleted or altered. The recordings will be destroyed after the approval and acceptance of the dissertation by the Graduate School of The University of Akron.

**Who to Contact With Questions:** If you have any questions about this study, you may call Claudia Sadler-Gerhardt at 330.972.7779, the Department of Counseling, or Dr. Cynthia Reynolds, 330.972.6748. This project has been reviewed and approved by The University of Akron Institutional Review Board. If you have any questions about your rights as a research participant, you may call the IRB at 330.972.7666 or 1.800.232.8790.

**Acceptance and Signature:** I have read the information provided above and all of my questions have been answered. I voluntarily agree to participate in this study. I will receive a copy of this consent form for my information.

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<tr>
<th>Participant Signature</th>
<th>Date</th>
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**Request for Permission to Audio-Tape:** I understand that the interview sessions involving myself and the researcher will be audio-taped, and that the taped interview will be transcribed without identifying information. I also understand that following the
completion of this study that the tape recordings will be erased. I voluntarily agree to allow audio-taping of my interviews.

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<th>Participant Signature</th>
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APPENDIX C

FLYER TO RECRUIT PARTICIPANTS
RESPONSES TO LIVING WITH BREAST CANCER

Claudia Sadler-Gerhardt, RN, PC,

a doctoral student at The University of Akron in Counseling,
is seeking women who have been diagnosed and treated for Breast Cancer within the past 5 years to participate in a study** about the experience of living with this condition.

Information provided through 2 face-to-face Interviews will help mental health providers to better understand what it means to be a survivor of breast cancer. Participants will receive a $15.00 gift certificate for their time after completing both interviews. True identities of participants will be kept confidential.

To learn more about this study or to volunteer to participate, please call Claudia Sadler-Gerhardt and leave a confidential voice mail message at 330.805.0362.

**This study has been approved by the Institutional Review Board for the Protection of Human Subjects at The University of Akron.
APPENDIX D

DEMOGRAPHIC QUESTIONNAIRE

How old are you? ___________

How old were you when you were diagnosed with breast cancer? _________

Do you have any blood relatives who have had breast cancer?   Yes   No

If yes, what relation to you was this person? _________________________________

How old was this relative at the time of diagnosis? ________

Have you had any genetic testing for breast cancer?   Yes   No

If yes, what kind? _______________________________________________________

What kind of treatment did you have for your breast cancer? (check all that apply)
   Surgery_____  Chemo ______  Radiation _______  Other __________

If “Other” please explain ________________________________________________

Where did you receive your treatment for breast cancer? __________________________

What race are you? ______________________________________________________

What is your occupation? __________________________________________________

What is the highest grade level of education you have completed?
   High school  1  2  3  4   College 1  2  3  4   Graduate school ______

Where do you live? ________________________________________________________

Who have been the most supportive people to you during your experience of breast
   cancer? (Check all that apply)
   Partner/Spouse_____ Parent/s ___ Children____ Friends/Neighbors _____
   Other relatives____ Minister/Rabbi/Religious Leader____ Other (who?)____
APPENDIX E

COMMUNITY MENTAL HEALTH RESOURCES

SUPPORT SERVICES FOR CANCER SURVIVORS AND FAMILIES

Stewart’s Caring Place—2955 W. Market, Akron, OH 330.836.1772
The Gathering Place—23300 Commerce Park, Cleveland, OH 216.595.9546
Support Group at Summa’s Breast & Imaging Center—95 Arch Street, Akron, OH 330.375.7082

HOSPITALS

Akron General Medical Center—330.344.1559
St. Thomas Hospital/Summa—330.379.5167

COMMUNITY MENTAL HEALTH SERVICES

Child Guidance & Family Solutions—330.762.0591
Clinic for Individual & Family Counseling—330.972.6822
The University of Akron, Carroll Hall
EMERGE Ministries—330.867.5603
Portage Path Behavioral Health—330.253.3100
Summit Center for Behavioral Sciences—330.836.6825
Summit Psychological Services—330.535.8181

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APPENDIX F

INTERVIEW GUIDE

The current research is designed to consider how women who have been diagnosed and treated for breast cancer have experienced their daily lives as a breast cancer survivor. The goal will be to discover an in-depth description of the phenomenon of living with breast cancer through the stories that the participants share. The participants will come from a purposeful sample having as much variability as possible. The following semi-structured interview questions will be asked of each participant during two audio-taped interviews held approximately two weeks apart. The interviews will be confidential, participants will chose a pseudonym to use, and the tapes will be available only to the research team.

1. How old were you when you found out you had breast cancer?
2. Is there anyone else in your family who has had breast cancer?
3. What was it like to learn you had breast cancer?
   Probes—
   a. How did you feel?
   b. How did you react at the news?
   c. Who did you tell?
4. How did your treatment go—surgery, chemotherapy, radiation?
5. How have you coped with/adjusted to the physical changes brought on by breast cancer or your treatment?
6. How have you changed as a result of your experience of breast cancer?
   Probes—
   a. Have the changes been positive or negative for you?
   b. How are your goals, purposes, priorities different?
   c. What has happened to your relationships during this time? Significant other, family, friends?
7. How do you experience being a breast cancer survivor?
   Probes—
   a. What is your identity as a survivor?
   b. What does it mean to you that breast cancer is a chronic disease?
   c. What does it meant to you that it can recur?
8. As you have coped with your breast cancer, have you ever experienced any of those “ah ha” moments—times of sudden change or new insights about life or living?
9. Please share with me what it is like for you to face your own possible mortality?
10. Is there anything else we haven’t discussed that you would like to share with me?
APPENDIX G

RESEARCHER JOURNAL

Below are selected excerpts from my researcher journal during my interview process.

5/9/07  My first interview! Wow! It’s actually here. This is a surgeon referral who called me, and we had such a nice conversation over the phone. I am looking forward to this. I am nervous, most especially about the taping. It reminds me of Prac! Plus my head is swimming and I feel as though I don’t have a clue. Help me relax, breathe, focus on the process.

After: What a neat interview! “Riley” is petite, tiny, dark short stubble hair, dark eyes that danced and sparkled. Talkative, self reflective—enthusiastic, open, forthcoming. Volunteered she is taking Zyban in lieu of antidepressant, sees a psychiatrist and has mild depression now. Scheduled for prophylactic mastectomy on the other breast this fall. She was a terrific 1st interviewee…sobering though, 5cm tumor and 3+nodes…aggressive. Want to be sure to discuss mortality at 2nd interview.

6/15/07  “Janis” 2nd interviewee…whew! What a difference from Riley. Janis was so hard to interview. Very pleasant, but made little eye contact, soft spoken, told all the medical details but didn’t have much to say about her reactions and feelings…described breast cancer as no big deal!!! I don’t know if because of her age (80) or maybe she’s just reserved, but she was tough. A lovely lady, but hard to interview. I felt discouraged, as
though I hadn’t done a very good job, need to figure out a way to open her up. I’ll have to really think this one through, as I think I am taking too much ownership about her interview. Maybe I need to use more concrete questions? But she has a master’s degree in history, so it’s not an intelligence issue. I think it may be related to her age and generation.

6/18/07 “Annie” Thank goodness! This interview was super! Otherwise, I’d consider throwing in the towel! Talk about a master storyteller! She was so inspiring and upbeat. I barely had to do a thing…almost like she really wanted to talk. I was really struck by her theme of giving back and also of how her cancer mirrored her friend’s cancer…that was a theme for their lives. She’s a strong Christian, so it should be interesting to analyze her faith perspective about mortality and meaning.

7/28/07 “Gretchen” was a referral from a colleague who is a woman of color. I realized I was getting all white women for participants, so I called this woman, asked her if she knew any survivors who are women of color. Gretchen was one of 2. Her story made me very sad, as she was treated so coldly by the hospital and medical staff. She was virtually ignored by her friends, and I just felt so badly for her. I discovered my bias, however, about the African American church. All the literature and my own anecdotal experience indicated that the Black church is supportive and caring. WRONG! At least in Gretchen’s case! No one did anything. But they did “offer to pray” and that makes me want to gag! Where is faith if not in works?

8/4/07 “Claire” I knew this one would be hard, as she is my daughter’s age and also her friend. We met out of state in a coffee shop in a college town. She was totally unconcerned about privacy issues and being in a public place. I felt a bit awkward at first,
but the place wasn’t too busy so that helped. I wondered what my transcriptionist was actually going to be able to hear on the tape however. As Claire talked, there were times I felt a definite counter transference regarding my daughter. I kept thinking, this could be my daughter sitting here fighting metastatic breast cancer. I felt that mother pain…I wanted to just give her a big hug! She is such a vibrant person, and so open and engaging…red hair and dazzling smile. You’d never know to look at her that she was taking chemotherapy. I definitely need to talk to my research “buddy” about her and put this in perspective. And is it a bad thing to feel that subjective caring for a participant? Isn’t that somehow that relational caring ethic that Noddings talks about?

She also hit some of my hot buttons with her story about how her church had been so unavailable to her. To think that they experienced such pain and yet were fearful and reluctant to have anyone in the church know about their struggles with faith and God! I really am angry just thinking about this! But what a fighter! Such an admirable woman—I felt privileged to meet her and hear her story.
The interview questions basically remained the same; however, I used them flexibly and in response to the participants’ stories. I just could not go down the list in a rote fashion, especially when throughout the process of their stories; they would usually cover most of the questions in one form or another. Annie would be a good example of this. The first question was to tell me a bit about their breast cancer, how old they were, how they found out, who they told first. Annie began talking and in her opening story shared her parallel story of her friend, and in addition to her age, discovery, and who she told, she gave me her context, told me about her medical care and treatment, her fears about body image, her faith, her support from friends and family, and her roller coaster experience of feelings (questions 1, 3, 4, and 7).

I very carefully and specifically addressed questions 8 about “ah ha” or sudden change and 9 about facing one’s own mortality. I felt these two questions would speak to the research questions about the change experience and the meaning of cancer and mortality. With Janis, since she seemed to be less self reflective, I altered the questions for the 2nd interview in terms of making them more concrete and less abstract. For example, I directly asked her if her style was to keep busy without taking time to think (in regards to her first experience of breast cancer), rather than giving her a more open-ended
“tell me about” question. She was willing to tell me about anything I asked; what was missing was how she felt and what it meant to her.

The second interviews were typically less structured. The purpose was for me to clarify and validate what I heard and understood from the first interviews. This was usually a rich interview, however. We had a relationship by that time, and most were fairly open and insightful by that time. Also, the mortality issue usually was the topic at the second interview, and they seemed to feel free to discuss how they felt. The first interviews were longer, about 1 ½ - 1 ¾ hours, and the second ones were usually about an hour.

Also, as the interviews progressed, I noticed that survivors were not experiencing a quantum type of change and were not recognizing themselves as having a chronic illness. That beginning analysis influenced me to add more detail to my question on the “ah ha” type change and to expand the description of what I was looking for. Although they disavowed having a chronic illness, there seemed to be common themes of feeling invisible or of not having permission to be sick. I felt it worthwhile to pursue this, even though it was not an original question, especially since the literature supported this concept. I also asked at the end if they would describe their experience of breast cancer to me, an addition to the questions.

Following the interviews, I converted the digital recordings to MP-3 files so that I could easily listen to them. My transcriptionist had computer software so that she could transcribe the interviews from the audio files. When I received the typed manuscript, I listened to the recording at the same time I read the transcript, to check for accuracy and
possible slips of real name usage. Then I would listen and re-listen and re-read the interviews to immerse myself into the data.

I then entered the typed transcript file into the NVivo-7 software on my computer. As I listened and read the screen, I highlighted what I saw as themes. NVivo has the ability to make themes into tree nodes, a hierarchical ordering system. For example, a tree node was “change after breast cancer” and under it I coded themes of priorities, mortality, relationships, behaviors, and purpose, and others. There were 54 places where a respondent referred to changed priorities, and 30 addressed mortality views. These were mentioned in 13 and 10 interviews respectively. As I worked through the highlighting of themes, it became easy to organize them into the ones addressed in the body of the chapters. I also could use a query function in the software. I recalled that Riley mentioned a loss of innocence. So I queried to find every place where innocence was mentioned. When there was a portion of text I wanted to quote, I could copy/paste it into my Word document, rather than re-typing it.

Unfortunately, the software is bulky, expensive, and not really user-friendly. I felt frustrated at many points during the analysis, and at times resorted to the old ways of colored post-its and highlighters. However, I am guessing that further use of the software would enable me to feel more enthusiastic about it.

After making an initial pass at analysis of about 2/3 of the interviews, I met with my research buddy to compare notes. She had read my rough draft, the case reports of each survivor, and their demographic questionnaires. Most of the time we agreed about the general themes. She even identified a few themes I had not considered. She also helped me to clarify and articulate my ideas and impressions of what was developing in
an organized manner. It was especially helpful to talk with her about my reactions to the survivors, my own re-living of my breast cancer experience, and my frustrations with the software. Not only is she a counselor, but she is also quite savvy with computer software, so her support was invaluable.
Thank you for agreeing to participate in the research on living with breast cancer. The first thing to do is to go over the informed consent document. You will notice that you are going to sign it twice, because you are agreeing to participate and also to be audio recorded. You will sign two forms, one to keep and one for my records. However, signing the form does not obligate you to continue participating in the research. Your participation is voluntary, and you may withdraw at any time, without any negative consequences to yourself.

The audio taping is confidential. First, you need to select a pseudonym or fake name that only you and I will know. That is to protect your true identity. Also, please do not mention your name, the name of your doctor, any family/friend names, or any other identifying information about yourself. After the interviews, the tapes will be transcribed into a written form, available only to me and my research team. Your real name will not appear anywhere. After the project is completed, the tapes will be destroyed.

You will then fill out a brief questionnaire giving some factual information about yourself and your breast cancer diagnosis and treatment. Please do not write your name on it.

There will be two separate interviews, lasting about 1 ½ hours each, and spaced about 2-4 weeks apart, depending upon your convenience. The second interview is for me
to clarify and verify that I have understood you correctly, and for you to add any additional information you may have thought of following our first interview. After your second interview, I will have a $15 gift certificate for you to thank you for your time.

Should you experience any distress during the interview, please feel free to talk to me about it. I am giving you this information sheet of community resources that you may wish to access if you feel you need some support for your feelings.

Do you have any questions? Is there anything you would like me to explain before we start?

Thank you very much for your time and participation.