LOST AND FOUND: CROSS CULTURAL PERSPECTIVES ON BREAST CANCER SURVIVOR WORK.

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Abstract of the Dissertation

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This study provides a Qualitative Research Synthesis of the unique characteristics of women in the survival phase of breast cancer across cultures: African American, Asian, Latina and Caucasian American. Studies included in this review included Women Survivors of Breast Cancer who were at least one year past primary cancer therapy, were currently cancer free, and were between the ages of 30 and 85 years of age. The search criteria excluded Stage IV cancer survivors and those who were receiving adjuvant therapy. Utilizing an apriori research protocol and a process of discovery, iterative review and quality appraisal, an initial identification of 1,946 studies was reduced to a final selection of sixteen articles that met the inclusion / exclusion criteria. The findings of these sixteen studies were synthesized into a new interpretation of the process of breast cancer survivor work.

The long time survival combined with the resulting lifelong issues exposed in the research, demonstrate the need for financial, medical, psychological and social support for breast cancer survivors and their families. Furthermore, the transformative nature of breast cancer exposes the excessive time and effort survivors spend doing survivorship. The various aspects of survivorship for breast cancer survivors include Emotion Work, Grief Work and Identity Work, which were previously considered distinct tasks. However, this study observed the integration of these factors in the formation a new model of *Survivor Work*. This is viewed as a dynamic theory that incorporates the processes of social interactionism in the production of a new identity formation. Additionally, the research revealed the impact of gendered identities and culture and/or ethnicity on the experience of the breast cancer survivor. Culture and/or ethnicity are shown to impact beliefs, socioeconomic status and the resulting perceptions of survivor identities, in the experience of the survivor work of breast cancer. This model may be further extended to other types of cancer and life-threatening illness where long-term survivorship is experienced.

This research has implications for policy, intervention and treatment of women survivors of breast cancer, which includes the necessity for social and health policies, ensuring the availability and accessibility of transitional care planning and culturally competent care. This should include targeted recruitment of cross cultural health care providers, and culturally specific support groups targeted towards more focused and specific ethnicities than typical of the currently utilized categories.

Dedication Page

I dedicate this dissertation to my children, whose support was strong and constant, and who never failed to tell me how proud they were of me. They are the treasures of my life. Next, to my grandchildren who are now here on this earth and to those yet to be born. My hope is that the stories they are told about their Nana will provoke them to pursue their dreams as wild as they may seem to others, and to trust their instincts. To the love of my life, my husband, partner, encourager, and editor, who picked me up every time I collapsed with exhaustion or tried to run way from the pressure and freed me from any responsibility except the dissertation and my teaching. Indeed, my success belongs to his dedication to make sure I fulfilled my dream.

To my grandfather, a traditional Italian man, who supported many of his relatives, including his daughter, in their pursuit of higher education in spite of pressures to the contrary. Finally, to my aunt Dr. Mary Cerbone, who was and will always be my inspiration, and whose loss will be felt for the rest of my life.

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Chapter 1 Introduction

Overview

Breast cancer survival is a relatively new phenomenon due to women's increased awareness of symptoms (Bray, McCarrow, & Parkin, 2004), advances in screening that lead to earlier diagnosis, and progress achieved in treatments (Berry, Cronin, Plevritis, Fryback, Clarke, Zelen, Mendelblatt, Yakovlev, Habbema & Feuer, 2005). Research in breast cancer survival is increasing exponentially, and this research targets the physical (Valenti, Prozio, Aielli, Verna, Cannita, Manno, Masedu, Marchetti & Ficorella al., 2008), psychological (Andersen, Farrar, Golden-Kreutz, Glaser, Emery, Crespin, Shapiro & Carson, 2004) emotional (Pasquini & Biondi, 2007), social (Till, 2003) and spiritual (Sammarco, 2004) issues that Women Survivors of Breast Cancer may face. Vivar and McQueen (2005) report, "Women with a history of breast cancer are the largest group of cancer survivors. While they may be disease-free, their cancer diagnosis has ongoing physical and psychosocial implications for their lives and well-being" (p. 520)

The existing research focuses on one or more of the above factors, sometimes grouping various combinations of these as Quality of Life issues and health related quality of life issues (Till, 2003; Kimman, Voogd, Dirksen, Falger, Hupperets, Keymeulen, Hebly, Dehing, Lambin & Boersna, 2007; Falagas, Zarkadoulia, Ioannidou, Peppas, Christodoulou & Rafailidis, 2007; Fedorchuk, Mendiondo & Matar, 2003). Much of this research is quantitative. Research has been conducted with individuals and/or groups within a specific cultural group but, due to the considerable effort required to conduct comprehensive, cross cultural qualitative research synthesis, and the difficulty in identifying participants for multiple cultures, few of these types of studies exist across cultures.

Interest in this topic arose from my personal journey with breast cancer and was furthered by conversations with other survivors of breast cancer and their health care providers. These conversations hinted at the fears, guilt, and shame that women feel about their role in getting breast cancer, their continued anxiety and fear about recurrences, the change in their awareness about death and dying, and the expectations of others when they transition from the status of breast cancer patient to survivor. In addition, the survivor of breast cancer experiences a dynamic that is, to some extent, unique. This is due to several factors related to gender, including body image and stigma, sexual identity and gendered roles. It appears that these issues are rarely, if ever, discussed openly. While there has been significant discussion regarding breast cancer survivorship, it has typically centered on the popular culture understanding of breast cancer as a transient event, which moves quickly from patient to survivor. This is very different from the ongoing nature of lived experience of the survivor and does not reflect their unarticulated thoughts and fears.

Development of Thought Life and Cancer.

Personal experience with breast cancer provided a significant shift in my *thought life* in the survival phase of breast cancer, which differs, from my thought life in the diagnosis and treatment phase. For purposes of this study, thought life refers to the automatic thoughts that come into one’s mind in reaction to what is seen, heard, or felt. For instance, most people who lose a child go on; they can work, accomplish, and experience joy, but they are never the same. Their life is continually framed by that loss (Lyubomirsky, Sousa & Dickerhoof, 2006). This dynamic seems to be the same for most people who have experienced a serious health issue, another form of loss and change (Weiss, 2005). Goffman (1963) speaks of the relationship between the stigmatized individual and ego identity, which frames the context of what one ought to think of oneself. The concept of thought life is used in religious literature and posits thoughts as a window into the heart and soul of a person. “As a man thinketh in his heart, so is he" (Proverbs 23:7, King James version). This passage seems to link thoughts to identity. In Buddhism, the idea of thought life is connected to character and actions (Claessens, 2009). In philosophy and psychology, thought life is alluded to as a prelude or reaction to behavior (Baer and Sauer, 2009). In Buddhism, philosophy and psychology, thoughts indicate who you are, your identity, and how you demonstrate who you are through your actions. In method acting, the actors forces themselves to think as if they are the character they are playing and the idea is that this will change the way they speak, look, or walk (Stanislavski, 1936). Interestingly, in this example, the actor uses a character’s supposed inner thoughts to impact the character’s physical characteristics. Sandstrom, Martin & Fine (2006) discuss processes that point to thought life. Both “reflexive and communicative activity – a process that includes…” subjective stream of consciousness and the “concept of self as a physical, social and moral being” as well as the process and construction and negotiation of meaning as a cognitive and emotional process that defines reality through “both thinking and feeling…” which are equally and mutually working together towards an interpretation of and an internal response to the situation (pp.51-52).

Most breast cancer survivors, including myself, move on from cancer, make changes and assume new directions in life. I am doing things that I only dreamed that I would do and am acutely aware of the preciousness of simple pleasures. This phenomenon is referred to as posttraumatic growth (Bellizzi & Blank, 2006) and positive meaning (Bower, Meyerowitz, Desmond, Bernaards, Rowland, & Ganz, 2005; Weiss, 2005). However, it is important to note that Bower et al. (2005) reported that positive meaning and vulnerability co-occur. Both positive meaning and a sense of vulnerability occurred when issues arose that caused an increase in the disruptiveness and stress of the cancer experience. This may be why one's thinking, or thought life, as a survivor of breast cancer is framed by the experience of cancer. Although the disease itself has been survived, there is still a threat to life that brings about existential issues, fear of recurrence, and a sense of vulnerability. Other factors may exacerbate the intensity and direction of the thoughts. These factors include but are not limited to the ideology of women as caregivers and, in illness narratives, as heroines who must be strong for the sake of those they love. Additionally, social propriety regarding illness requires that one remain upbeat at the very least. Diedrich (2007) discusses Jackie Stacey's critiques of Western popular cancer narratives that find "an overcoming of loss and failure" to be the "socially sanctioned illness narratives" (p54). Diedrich instead compares the American and British narratives. She believes that British narratives focus on the "cultivation of the ironic self" while American narratives focus "on the cultivation of the improved self" (p.55) I think that the improved self is the outcome of overcoming loss, failure, shame and stigma. However, there is a strong preference for silence, especially when it is cancer. This may produce the perceived need for the hidden, or secret, phenomena rather than participation in the work of Survivorship which includes identity, emotion and grief work.

This framework impacts me in every area of my life in the present phase of survival; yet I feel compelled to keep these thoughts to myself. Though I have heard breast cancer survivors allude to this and the data collected from these survivors refers to this (Lethborg, Kissane, Burns & Snyder, 2000; Zunkel, 2002; Schnipper, 2003; Frankel, 1988; Phillips, Gray, Davis & Fitch, 1996; Smith, 1983), they have not captured the sum of these issues in a single, distinct, subject related to the survival experience. I call this the hidden nature of cancer survival and believe that survivor work is necessary to deal with the life long process and work of their experience of breast cancer.

Combined with my focus on the experiences of breast cancer survival, I have a deep interest in cross-cultural studies that was initiated by work done as a research assistant in a study that focused on disparities in health care for pregnant African American women (Francis, Berger, Giardini, Steinman & Kim, 2009). Additionally, I was inspired by research conducted by Mary Abrums (2000) about perceptions of health and illness across cultures. This interest was supported and furthered by my work as a clinician in a community mental health agency where clients often voiced concerns related to cultural insensitivity and bias. My commitment to understanding differing cultural frames in health and illness is no less than that of understanding the experience of breast cancer survival, which is impacted by the unique cultural meanings of each culture to illness, particularly one that contains the word ‘cancer’.

Purpose of the Study

The purpose of conducting this study was to appraise, synthesize and interpret the findings of the existing literature and research that explores the meaning, value, and emotional experience of surviving breast cancer, and to discover if and how it relates to breast cancer survival across cultures. The cultural groups that are the focus of this study are African American, Asian American, Caucasian, and American Latina women. To meet this purpose, a Qualitative Research Synthesis of the literature and research on the unique characteristics of the survival phase of breast cancer was conducted. Included was an exploration of the further influence of culture upon these women. Previous studies have been conducted within a particular cultural group (Jones & Chilton, 2002; Abrums, 2000; Mo, 1992; Wong-Kim, Sun, Merighi, & Chow, 2005) and between various cultural groups (Bourjolly, Barg & Hischman, 2003), and have shown that culture is one factor that influences the breast cancer survivor in coping and living after breast cancer. Their exploration and discussion of culture is primarily concerned with the cultural sensitivity of health care providers and the cultural beliefs about illness held by various cultural groups, rather than the women's views of their experiences, as it relates to the work of breast cancer survivorship (Williams, 2002; Ashing-Giwa, Padilla, Kraemer, Wright, Coscarelli, Clayton, Williams & Hills, 2004).

Research Questions

This research provides a conceptual framework for the following research questions:

1. What is the meaning and experience of breast cancer survival for American women across cultures?
2. What is the shared meaning and experience of surviving breast cancer across cultures? What differs across cultures?
3. Does this meaning and experience result in a reluctance (either articulated or non-articulated) to reveal that experience to medical practitioners, other survivors, family members and the community at large?

Significance of the Study

This study provides insight into the meaning and experience of breast cancer survival both individually and as a part of the group of women at the survival phase of breast cancer, as well as part of a specific cultural group, each with its own cultural norms and meanings. This adds knowledge and understanding to treatment and policy decisions regarding the trajectory of survivorship in cancer care. For instance, with the added insight from this study, health care providers may better recognize and respond to the needs of breast cancer survivors once the significance of survivorship is understood. This introduces the need for continued support beyond the usual time frame of the treatment and diagnosis phase since survivorship has ongoing issues that wax and wane throughout the survivor's life. The issue of cultural differences should propel health care practitioners to re-examine their current policies and practices to provide for those cultural differences within their own practice and through support systems that are sensitive to specific cultural groups. Policy initiatives that reframe the current mainstream ideologies of health and illness should be exposed and reinterpreted for breast cancer survivors across various cultures to positively impact service delivery by health and human service professionals. Healthcare professionals should be re-trained to assist these survivors to explore these meanings, experiences and hidden thoughts that they are socialized to keep silent about. A more holistic approach to care may be initiated that provides support to the survivor as they negotiate their new identity. Healthcare professionals can provide the tools so that survivors can successfully reconstruct their new identity through the effective integration of survivorship through emotion, grief and identity work. Methods for releasing and managing the negative aspects of thought life, should also be considered by the healthcare system to increase the quality of life for breast cancer survivors, and the knowledge base for understanding the lived experience of breast cancer survival.

Summary

The issues of breast cancer survivorship must be addressed due to the increasing number of survivors each year. Physical issues, including body image and residual pain and discomfort, as well as, psychological, emotional, social, and spiritual issues impact not only these survivors, but their families, friends, and the communities where they live, work and play. Health care workers across various disciplines who provide service to breast cancer survivors may be either unaware of or overwhelmed by the issues that are outside of their area of expertise and by the increasing numbers of survivors that they are treating. Yet research shows that a correlation of interventions in one discipline impacts outcome in another. Therefore a coordinated approach to intervention that treats the person as a whole is needed (Andersen et al., 2004). Correspondingly, in a culturally diverse nation, differences in understanding, value and meaning, as well as similarities, must be understood to better serve all breast cancer survivors and provide the support necessary to develop culturally competent care. Studies demonstrate that cultural differences can impact delivery, compliance, and outcomes for patients (Napoles-Springer, Ortiz, O'Brien & Diaz-Mendez, 2008; Betancourt, Green, Carrillo & Ananeh-Firempong, 2003). Within the present health care system, where health care disparities across cultures are just beginning to be acknowledged but are rarely addressed, we know that culturally competent care is critical to the effectiveness of interventions. The process of surviving breast cancer must be explored and understood by providers of services from the survivor's standpoint in order to provide the necessary care and services that treat them holistically and increase quality of life for all survivors, no matter their culture.

Chapter 2 Literature Review

Introduction

It is important to note the difference between a Literature Review used to understand the broad issues and concepts related to understanding the historical background of breast cancer survival research, and the methodology of the prescribed process of a qualitative research synthesis. The section below is the Literature Review, which provides an examination of the broader issues and concepts related to the history and background of breast cancer survival. The latter section under Methodology includes the research protocol which identifies the inclusion and exclusion criteria of the qualitative research synthesis for the articles that were studied, and the process used to synthesize the findings of the research.

Early diagnoses through improved screening processes for breast cancer have had a positive impact on early detection of breast cancer. This has increased breast cancer survival rates, thus creating a large number of women in the survival phase of breast cancer who continue to require medical, physical, psychological and social oversight and care, as well as research based information on meeting those needs. (Gotay & Pagano, 2007; Mahoney, Bird, Cooke & Ball, 1977). A cursory review of this phenomenon reveals an emerging body of research in both quantitative and qualitative form on understanding survival.

The early studies framed this new trajectory of survival as the stage of remission, and recognized the need to address the unique challenges of this stage, including quality of life factors (Wood & McWilliam, 1996). Later studies acknowledged the concept of long-term survivorship and the need to address the unique psychosocial issues faced by breast cancer survivors who were living longer (Ahles, Saykin, Furstenberg, Cole, Mott, Titus-Ernstoff, Skalla, Bakitas, & Silberfarb, 2005; Bellizzi & Blank, 2006; Bower, et al., 2005). Frank (1995), who is most interested in survivorship, speaks of a community of those who are chronically ill or effectively well, and yet have not been cured, and therefore live in a remission society. They are patients while nevertheless learning how to live a good life. Similar to the identity shifts of colonial peoples in history, the lived experience of having had breast cancer is part of a survivor's embodied identity. Frank views them as "post-colonial in their construction of self" (p10). An equally frustrating issue is that knowledge of this colony is, in many ways, dealt with like any other colonized group, by those that laid claim to the bodies rather than those that live in the bodies. Even long term survivors of breast cancer lack permanent citizenship, according to a survivor in Frank's book. The citizenship of every breast cancer survivor is, at the very least, questioned with every yearly checkup; every pain or symptom that represents the citizenship of breast cancer though they are proclaimed cured. Frank proposes seeing cancer survivors as both well and sick rather than either one or the other.

While breast cancer detection and treatment still lags for minority groups, research leading to policy changes is beginning to have an impact on those populations. Few of these studies aim to understand what survival looks and feels like for women survivors across cultures. An exception is Ashing-Giwa, et al. (2004) who conducted focus group interviews with women survivors of breast cancer across cultural groups and key informant interviews with health care professionals. Their broad study,

> … accomplishes two goals: it adds to the sparse literature concerning the psychosocial sequelae of breast cancer among women of color, and it increases our knowledge of specific cultural influences (e.g. dietary practices, coping) and socio-ecological factors on Health-related Quality of Life More importantly, the study addresses areas that have not been studied before, specifically, an in-depth

> study on breast cancer survivors' quality of life comparing multiple ethnic groups in the U.S. (p. 408).

Data in this study allude to the hidden nature of survival (Ashing-Giwa, et al., 2004). All of the above mentioned studies confirm and elucidate the issues that breast cancer survivors are dealing with silently: (a) relationship problems (Rendle, 1997); (b) physical issues, including fatigue, weakness and diminished performance related to treatment (Ahles, et al., 2005; Fallowfield, Hall, Maquire & Baum, 1990); (c) concerns about cognitive function (Burgess, Cornelius, et al, 2005); (d) emotional issues related to body image and health image, and sexual health which includes sexuality, performance and desire (Sammarco, 2004; Pasquini & Biondi, 2007); (e) coping strategies that are restrictive and harmful (Fallowfield & Baum, 1989); (f) anxiety and re-traumatization by frequent tests and procedures ordered by health care providers (Fallowfield, Baum & Maguire, 1987); (g) financial problems (Heck, Wagener, Schatzkin, Devesa, & Breen, 1997); and (h) career problems (Satariano & DeLorenze, 1996; Rendle, 1997). These issues lead to psychological, cognitive, physical and sexual distress that is not usually discussed openly.

Unfortunately, there is little information in the literature that compares these phenomena across cultures. Abrum's (2000) ethnography and Ashing-Giwa, et al., (2004) both demonstrate that cultural distinctions may exist in the meanings of health across cultural groups. They state that "coping responses illustrate common human characteristics, yet there were profound cultural differences" in the manifestations of those responses (Ashing-Giwa, et al., 2004, p. 426). For most of the women, these coping responses were related to the role expectations for wives, mothers and for women in general. The distinctions between married or single and/or between mothers or women who were not mothers were not many or great with the exception of younger and single women. Younger and single women feared that cancer would be a deterrent to their ability to find a partner/husband, especially if their treatment hindered their ability to bear children. All the women had concerns about getting help and being a burden. For instance, Asian American and Latina women were reluctant to burden their families and stated that they acted and spoke as if nothing was wrong. African American women mentioned role expectations and were emphatic about spirituality as the major source of comfort, which was found within their church community. Caucasian women report using a variety of spiritual and coping practices. Not surprisingly, the more acculturated or assimilated one was with the dominant middle class American culture, the farther they were from their culture of origin's meanings and responses to being a breast cancer survivor. This will be discussed more fully in the section titled Results.

Review of Relevant Research

Several recurring themes emerged during the process of reviewing the related literature. These include survival (or survivorship), psychosocial issues related to breast cancer survivors, quality of life factors, the impact of culture on the experience of the survivor, and the hidden thought life of the survivor. Due to the intersection of race, class and gender, socioecological impact such as life burdens, family life, neighborhood and environmental contexts were especially relevant for African American breast cancer survivors (Ashing-Giwa, 1999). The literature demonstrated that these issues might also impact Latina's.

Psychosocial issues.

Psychosocial concerns of cancer survivors in general, include psychological, physical, emotional, social and spiritual issues. Though many of these same issues exist for survivors of other cancers, for women survivors of breast cancer it also involves the sense of gendered meaning, body image, sexuality and sexual function which is embodied in the understanding and perception of womanhood. These can be grouped in either (a) negative terms, e.g. fear of recurrence, depression, physical compromise, uncertainty, existential / spiritual, employment, and insurance problems; or (b) positive terms, e.g. feelings of gratitude and good fortune, sense of self-esteem and mastery (Hewitt, Greenfield & Stovall, 2005). Much has been written regarding the impact of various treatment protocols (e.g. breast conservation vs. radical mastectomy) and cancer chemotherapy on the post-treatment psychological outcomes of breast cancer survivors (Fallowfield, etal., 1990; Nerenz, Love, Leventhal, & Easterling, 1986). Depression, anxiety, psychiatric morbidity, and traumatic stressors are recurring themes that are being explored with regards to effective treatment policies and support systems. For some women one or more of these supports are helpful but certainly not all women are comfortable in the support settings, some of which may try to socialize women into silence and adopt what the support system tells them to rather than to explore their feelings (Fedorchuk, etal., 2003; Pasquini & Biondi, 2007; Fallowfield & Baum, 1989; Burgess, Cornelius, Love, Graham, Richards, & Ramirez, 2005).

Body Image, Sexuality, Sexual Function and Desire.

The issues of women survivors of breast cancer related to body image; sexuality; sexual function and desire are placed within the category of psychosocial and quality of life issues in most studies. However, issues of body image as it relates to sexual self-esteem, sexuality, sexual function, desire and for young survivors of breast cancer, infertility, are unique to women breast cancer survivors and therefore warrants a separate section in this paper.

Research utilizing the Cancer Rehabilitation Evaluation System (CARES), suggests that body image and sexuality are related and in turn impact desire and sexual function (Avis, Crawford & Manuel, 2005; Walsh, 2005). Further research indicates that there may also be a resulting impact to psychological well-being. Taylor, Lamdan, Siegel, Shelby, Hrywna and

Moran-Klimi (2002) reviewed the impact of various treatments on the breast cancer survivor's sense of sexual attractiveness through quantitative methods. The sample included 91 African American women survivors of breast cancer who were assessed at 3 months following surgery (evenly divided between lumpectomy and mastectomy) and again at 7 months. Regression analysis revealed a statistically significant correlation between psychological well-being and a self-perception of sexual attractiveness. However, the researchers determined that impact upon sexual attractiveness was not necessarily linked to the type of surgery, but was strongest in those survivors who had undergone chemotherapy and surgery, leading to the conclusion that the compounding effects of disfigurement, hair loss, skin discoloration and weight gain upon body image had the strongest resulting impact upon the survivors' sense of sexual attractiveness and therefore psychological well-being. The authors suggest that psychosocial support programs for sexual attractiveness be an added component for African American survivors of breast cancer.

The most salient issues faced by breast cancer survivors are related to gendered meanings and are important to both the survivor and society. Garland-Thomson (2009) refers to breasts as "ubiquitous cultural icons", being both noted and notable. "From the sacred fount of the Maria Lactans, the titillating cleavage of Miss America, the ample bosom of Mammy, to the erotic blast of the Playboy centerfold, the sight of breasts signifies woman. As both symbol and flesh, no other bodily mark of sexual identity is so routinely or ritualistically offered up to the public eye" (p. 141).

This is in contrast to other sexual body parts such as penises and vaginas that "for the most part demurely decline stares. Breasts, by contrast, are in your face" (p. 141). Breasts represent the feminine in the sexual and maternal, both within the realm of womanhood, gender identity and gendered roles. Breasts may be viewed as the embodiment of womanhood.

Femininity and sexuality, as situated in the form of the breast may create the case for breast reconstruction as a means of reclaiming corporal elements of identity. In fact, the review of the literature demonstrates that many health care providers who treat women with breast cancer suggest that breast reconstruction or use of a prosthesis as a means to help women feel and look normal (Gould, Grassau, Manthorne, Gray & Fitch, 2006; Huber, Ramnarace, & McCaffrey, 2006). In contrast, the study by Compvoets (2006) demonstrated that it is not breast reconstruction but their renegotiation of self as unbreasted that provides the restoration of true womanhood.

The literature related to breast cancer survival for younger women identified those women who were from 45-50 years of age and younger or included premenopausal women when no age was mentioned. One article's title best communicated younger women survivors of breast cancer concerns: "Nothing fit me': nationwide consultations with young women with breast cancer". This lack of 'fit' had to do with receiving the appropriate information, support, and resource recommendations for diagnoses, treatment and survivorship that were particular and relevant to young women with breast cancer (Gould, et al., 2006). A significant area of concern for younger breast cancer survivors was related to communication and partner support issues. The provision of information from health care providers about how to best navigate their illness both actively and passively with husbands/partners and children was identified as an opportunity for intervention (Walsh, Manuel & Avis, 2005). These women also struggled with managing their illness and with maintaining the energy necessary to continue their role as primary caregiver and partners, and expressed fear of not being able to raise their children adequately.

The commonly reported issues of breast cancer and its treatment include not only the physical and related emotional issues but additional issues related to "decreased sexual desire, sexual arousal difficulties, change in responsiveness to physical sensations, experience of pain during intercourse, and loss of pleasure from sex. Chemotherapy, radiation therapy, fatigue, medications, and other comorbid medical illnesses may impair female sexual response" (Fleming & Kleinbart, 2001, p. 215). These issues, though experienced by women of all ages, seem to be a larger issue for younger women rather than older women.

Biglia, Moggio, Peano, Sgandurra, Ponzone, Nappi & Sismondi (2010) focused on pre-menopausal breast cancer survivors in their study and revealed a significant impact to young women due to surgical and adjuvant therapies. This produced negative meanings such as menopausal symptoms, impacts to sexuality and partner relationship, depression, and body image. Body image issues were mostly due to chemotherapy, which yielded increased body weight and android fat disposition, problematic issues for young women who are generally concerned with body image. Life stage is an important consideration across many social issues and is no less important for young women survivors of breast cancer than it is with older women or with any other cultural distinction.

In a study of 50 Asian Women with a median age of 50, the researchers reported that, after diagnoses of breast cancer, 36% of the women completely stopped sex, 18% stopped gradually and 8% continued their sexual relationship at the time of interviews. Approximately one third of the participants believed that sex could cause a recurrence of breast cancer while another third thought that breast cancer could be transmitted through sexual intercourse. This study demonstrated how myths germane to a culture could shape meanings of breast cancer (Khoo, 2009).

Quality of Life factors.

Quality of Life is a typically subjective measure that has been effectively operationalized via the use of the standardized global health/quality of life scale of the European Organization for Research and Treatment of Cancer (Aaronson, Bergman, Bullinger, Cull, Duez, Filiberti, Flechtner, Fleishman, & de Haes, 1993). A primary focus of research has been on those behaviors and practices that improve quality of life for women survivors of breast cancer. These include evaluation of support groups (Till, 2003; Waller & Batt, 1995), on-line / internet resources as a supporting framework (Ziebland, Chapple, Dumelow, Evans, Prinjha, & Rozmovits, 2004; Meier, Lyons, Frydma, Forlenza & Rimer, 2007; Whitten, Kreps, & Eastin, 2005; Schwitzer, 2002); physical exercise (Valenti, et al., 2008), factors associated with re-employment (Satariano & DeLorenze, 1996); and the primary effect of positive, supportive interactions with physicians providing diagnosis and treatment for breast cancer survivors (Leydon, Boulton, Moynihan, Jones, Mossman, Boudioni, & McPherson, 2000; Back & Curtis, 2002; Slevin, 1992). Additional relationships between quality of life and age at diagnosis have been explored (Cimprich, Ronis, & Martinez-Ramos, 2002), as well as forms of adjuvant therapy and quality of life (Hewitt, et al., 2005; Ahles, et al., 2005) leading to long-term predictors of quality of life outcomes of breast cancer survivors. Adjuvant therapy is defined as any treatment after primary therapy, such as radiation and chemotherapy. This does not include Complementary and Alternative Medicine as defined by the Mayo Clinic and The National Cancer Institute.

Thought life of the Woman Survivor of Breast Cancer.

The concept of the thought life is one that, in many cases, must be inferred from the existing literature. Several of the qualitative studies exploring breast cancer survival and survivorship reveal articulated (and non-articulated) thoughts, fears and cognitive strategies common to breast cancer survivors. These include: (a) loss of control; (b) empowerment; (c) isolation; (d) determination; (e) fatalism; (f) protective buffering of family members; and (g) the Damocles syndrome (Hewitt, et al., 2005; Lethborg, et al, 2002; Phillips, et al., 1996; Fallowfield, 1993). Non-articulated thoughts are often perceived as disengagement with the therapeutic process and result in negative outcomes for palliative treatment (Segerstrom, 2005; Leydon, et al, 1987; Wood & McWilliam, 1996). Susan Sontag in *Illness as Metaphor* (1978) wishes to remove metaphors about illness in order to free the patient from the bondage that these metaphors place on them: their character, personality, emotional tenor and level of strength. Indeed, she succeeds in eliminating the embedded myths of cancer that existed in the late 1970's, which viewed both cancer and repressed persons as being synonymous. However, the issue of responsibility for getting cancer and for recovering from cancer seems to have shifted from an inherent personality flaw to the issue of poor lifestyle choices that burden society. Even with recent changes in legislation for health care reform, the United States of America is a nation with a strained and absent health care system. Additionally, there is a counterforce that creates an easy exchange for breast cancer survivors as heroines, which is another imposed identity to be managed. Frank (1995) encounters something similar to this when speaking with a parent of a mentally disabled adult child. After attending a support group for parents she states, "We do not tell our own truth" (p. 63). This is true across illnesses. It places the patient/survivor as responsible for a story that removes anguish and frustrations and testifies to the good fight of the patient and doctors for a good outcome. Frank sees this cultural stoicism as bordering on denial. This is seen in breast cancer survivors when their identities are stigmatized across various settings and within their conflicting role requirements, cultural constraints and norms. Therefore, they manage these identities differently across roles and cultures by shifting cognitive processes, i.e. thought life, through cognitive reframing. This identity management helps them to be acceptable to others' views of what a survivor should be able to accomplish (Stets &Turner, 2006; Frank, 1995).

Survival (Survivorship).

The concept of survival and survivorship has evolved over the last decade from the prior classification of remission to recognition of the new trajectory that bridges the transition from cancer patient to cancer survivor (Hewitt, et al., 2006). The definition of what constitutes survivorship has also changed from the previously accepted views of survivorship as beginning at15 - 20 years post occurrence, to a 5 -10 year post occurrence (Burns, Freund, Lees, Hulburt, & Grace, 1979; Irwin, 1971; McCormick, 1953), to a phase that begins as early as the end point of treatment and most recently, survivorship beginning at diagnosis. (East, 2000; Lethborg, et al., 2000). With this new definition, a shift in primary focus from palliative care, to recognition of the need to understand and address the unique issues of survivorship has emerged. These issues range from perceptive psychological outcomes of positive meaning and vulnerability, and posttraumatic psychological growth (Bower, et al., 2005; Bellizzi & Blank, 2006) to collaborative strategies for follow-up care from family physicians (Wood & McWilliam, 1996; Grunfeld, 2005) and psychosocial support (Fedorchuk, et al., 2003).

The various aspects of the process, or work of survivorship (which I have identified as "survivor work") includes emotion work, grief work and identity work. These works have been explored as distinct processes, but little has been reported that addresses the integration of these factors and the resulting impact on survivor identity.

Emotion work.

The theoretical construct of the sociology of emotions contains predominantly five (5) streams: dramaturgical, symbolic interactionist; interaction ritual; power and status; and exchange theories (Turner & Stets, 2006). The literature providing the basis and application of these theories to emotion management, emotion regulation and emotion work is abundant, however, the literature and research specific to illness is less so. Beyond that, there is a dearth of research specific to the breast cancer survival experience. References to emotion work and breast cancer survival primarily lean upon three (3) of these theories: dramaturgical, symbolic interactionist and power and status. The concept of emotion work, as posited herein, refers to the process of either managing (or regulating) one's emotions for one's own benefit, or the effort required to manage one's emotions in order to influence the emotions of another (emotion work or unpaid labor). The concept of emotion work was first developed by Hochschild (1983) in the commercialized context of interactions of flight attendants with passengers and one another. The term unpaid labor has been used in the context of the typical gender specific work of the woman as being primarily responsible for the management of the emotions of others (Yoo, Aviv, Levine, Ewing & Au, 2010).

The majority of research specific to emotion work within breast cancer survival (be it related to management, regulation or unpaid labor) has been conducted outside of the United States, primarily in Canada, Great Britain, northern Europe, New Zealand and Australia. This is not unexpected, since the studies are largely intervention based and developed in environments with strong socialized healthcare systems that encourage preventative rather than reactive approaches to treatment. In addition, the emphasis of theory related to the Sociology of Emotions in the U.S., up until the 1970's, had been upon the positivist view of the psychophysiological nature of emotions, rather than on the more recently developed social interaction framework of emotions (Kemper, 1978).

Interventions and models that focused on emotion regulation for breast cancer survivors contain strategies for controlling stress (Antoni, Lehman, Kilbourn, Boyers, Culver, Alferi & Carver 2001; Bridge, Benson, Pietroni & Priest, 1988; Carlson, Speca, Patel & Goodey, 2003). Cameron, Booth, Schlatter, Ziginskas & Harman (2007) introduce the ‘Common Sense Model’, an emotion regulation system to control distress. The strategies are: “(1) Alteration of emotional arousal such as by using relaxation techniques; (2) Expression (versus suppression) of emotions; and (3) Cognitive change or reappraisal, such as finding benefits in the illness experience and enhancing perceptions of control and invulnerability to disease progression.” (p. 171). While this is an intervention-based framework, it is relevant that the model recognizes the impact of the mind-body connection in all three strategies, the importance of expression as a positive activity and cognitive reappraisal as decreasing the perceptions of risk of recurrence. In a sense, this model provides concrete steps for doing emotion work.

Yoo, et al. (2010), in an article that focused on the sociological relationship between survivorship and emotions, reported that women utilized various strategies for disclosure and emotion work during the treatment decision-making phase. This work included: “managing others’ worry; protecting and soothing others; and educating and instructing others” (pp. 209-210) and required a great deal of ‘work’ and effort at a critical time in the breast cancer journey. However, a large number of the women reported disclosure without emotion management. This reduced the stress of the work that goes into managing others emotions and led to increased social support.

Grief work.

Grief work can be defined as the "psychological process of coping with a significant loss" (Blatner, 2000, p. 41), or the "emotion felt in the face of irretrievable loss" (Charmaz & Milligan, 2007, p. 518). Grief work is typically seen as a subset of emotion work, and as such, the focus of literature on this topic is similarly restricted to studies proposing appropriate interventions to facilitate the work (Goldsworthy, 2005). Social theorists including Kubler-Ross, Bowlbly and Engel, in general, have provided the theoretical framework for grief work. The common thread in these frameworks is the staging of emotional work related to the grieving process. These stages vary from four (4) to seven (7) and are typically seen as being sequential in nature, although the possible cyclical nature of stages is recognized (Worthington, 1994). Staging specific to the breast cancer survival experience has been proposed that identifies five stages (Zuckweiler, 2012), which are not sequential in nature, but are subject to re-cycling upon recurring triggers. This has been recognized in the literature specific to intervention based studies on grief factors and breast cancer (Tacon, 2011; Kissane, 1997).

When taken in the context of social interactions, typical of the breast cancer survivorship experience, Grief work takes on similar dimensions to that of emotion work. The experience of the grieving survivor in the context of breast cancer survival is one who has experienced, and who continues to re-experience, a loss. The loss may range from the physical (hair, breast, sexual function), to the existential loss of self, and self-control (Tacon, 2011). The emotion work within the grieving process is similarly socially constructed, and is subject to the same forces of dramaturgical stress, power and status as the balance of the work of survivorship for the breast cancer survivor.

The interventions proposed by several authors for the grieving survivor are focused on coping strategies to improve quality of life in early stages of diagnosis and treatment. These include cognitive group therapy (Kissane, 1997; Spiegel & Spira, 1993) mindfulness training (Tacon, 2011; Carlson & Garland, 2005; Sagula & Rice, 2004) and other types of coping skills training (Rose, 1989).

Identity work.

The concept of survivorship can be seen as the adoption of a survivor identity (Deimling, Bowman & Wagner, 2007). The work of adopting this identity has been defined in the literature regarding cancer, and specifically breast cancer survival, as "the process of patients' evaluations of the meaning of their illness within the actual context of ongoing, organized social relationships, including the medical system" (Mathieson & Henderikus, 1995, p. 283). Little, Paul, Jordens and Sayers (2002), further explore the development of a personal identity of survival within prevailing theoretical constructs as "being defined by embodiment, continuity and memory" (p. 171).

An understanding of the framing of the cancer survivor identity is important to this discussion. Society and popular culture, over the past 30 years, has shifted from an understanding of cancer as a death sentence to one of survivorship, to the extent that, for the breast cancer survivor, survivorship begins at the moment of diagnosis. This is due, in part, to the advances in visibility and resultant insurance reimbursement that have improved breast cancer screening participation, and improvements in effective, targeted treatment programs. These changes in societal views are reflected in the work towards, and adoption of the survivor identity (Kaiser, 2008; Deimling, et al., 2007). However, the identity as survivor is not universally accepted by all breast cancer survivors (Kaiser, 2008). Park, Zlateva & Blank (2009) refer to multiple identities (or labels) that may be self-adopted after cancer. These form a type of continuum that ranges from the Victim label, progresses to the Patient and Person with Cancer and ends with the Survivor label. Along this progression, from the Victim to Survivor, increasing levels of psychological well-being are seen, along with improvement of affect from negative to positive, and the evidence of post-traumatic growth with adoption of the survivor label.

In line with established identity theory, the work of adopting the survivor identity (survivor work), can be linked to both positive and negative outcomes. As a result of the impact of the life event stressors experience by the breast cancer survivor, a reconstruction of the prominence of roles, or identities, and disruption of the salience hierarchy is typically experienced (Stryker & Serpe, 1982). Cancer becomes enduringly prominent … all else fades (Deimling, et al., 2007). Identities that had gained prominence prior to cancer (e.g., mother, wife, professional, friend) are challenged in this new order and may be replaced by illness-related identities. Gender specific cancers (i.e. breast and prostate cancer) carry with them an additional dimension of gender specific role strain and sexuality. The strain on role performance with others and its disabling effects, result in guilt and self-blame in the breast cancer survivor (2007). On the positive side, a number of the researchers pointed to opportunities for personal growth, improved well-being, altruistic pursuits and positive re-framing and re-appraisal (Park, et al., 2009; Zebrack, 2000; Kaiser, 2008; Deimling, et al., 2007).

Various frameworks of the identity work as a survivor have been posited, depending upon the theoretic approach taken by the researcher. Mathieson & Henerikus (1995) refer to the relationship between psychological control and effective adjustment, within the context of a cognitive adaptation model. They emphasize the elements of disrupted feelings of fit, and indicators of a renegotiated identity which lead to biographical work that form the lifelong process of narrative reframing. Additional frameworks along the social constructionist, and symbolic interactionist models refer to the extreme distress resulting from the impact of various factors, external to the breast cancer survivor. This includes psychological, social, physical, spiritual, etc. stressors, which cause further disruption to, and conflict within, the identities associated with established social roles (Zebrack, 2000; Waskul & van der Riet, 2002). Little, et al. (2002) refers to the perspective of John Locke as it relates to the continuity of consciousness (and memory) as a qualification of personal identity. They point to the disruption of future memory as opposed to plans or expectations as the primary threat to identity in that it impedes continuity and the ability to construct a meaningful future. In their perspective, identity is both personally and socially constructed, and is reflexively joined. Further, with regard to the social constructionist model, Kaiser (2008) speaks of a dualistic approach to framing survivorship. On one hand, survivorship can be seen as an existing framework, or cultural tool for the disease experience and resulting identity. This is evident in the popularization of the pink ribbon campaign, cancer walks and other opportunities to practice being a survivor. On the other hand, the breast cancer survivor may follow an alternate approach of craftwork, defined by Frank (2003), which requires a self-conscious construction of the survivor’s life and meaning.

As addressed earlier with regard to body image, sexuality, sexual function and desire, final recognition should be made of the impact of body image and stigma upon the reconstructed identity. Waskul and van der Reit (2002) refer to the damage to the self, due to the abject embodiment of the cancer experience. They speak of the embodiment as being at once incidental and stigmatic to the survivor. The incidental force of the abject embodiment is the strongest during the treatment phase. This is the period where the body is handed over for medical attention. It is no longer to be trusted, it has betrayed the survivor, and as a result, the self disconnects from the body, leading to alienation and feelings of powerlessness. Beyond treatment, the abject embodiment leads to a loss of dignity, as it impacts all others relationships. The “inherent trust in the fidelity of their bodies - those previously ‘natural’ relationships - have forever been undermined” (Waskul and van der Reit 2002, p. 510). The process of identity reconstruction is, likewise, forever impacted.

Impact of culture.

As reported by Ashing-Giwa, et al. (2004), there is a scarcity of information and research on breast cancer survival from diverse ethnic and socioeconomic backgrounds. When the common factors of quality of life, psychosocial and physical concerns, or cancer recurrence are explored across cultural and ethnic boundaries, the differential effects are revealed. Women respond differently to strategies of prevention, treatment and post-treatment support, depending on their cultural paradigm (Mo, 1992; Wong-Kim, et al., 2005; Jones & Chilton, 2002; Bourjolly, et al., 2003; Rosenwaike, 1988; Abrums, 2000). In the qualitative study, comparing foreign-born Chinese breast cancer survivors to U.S. born Chinese women conducted by Wong-Kim, et al. (2005), the researchers “learned that cancer survivors need culturally appropriate interventions, that will help improve their quality of life” (p.11). These interventions could include culturally sensitive support services such as in-home services provided in their native languages or improving relational networks within their communities. This study demonstrates that culture varies within cultural groups depending on country of origin. This variation often determines beliefs and socioeconomic status which in turn impact beliefs about, perceptions of, and experiences of breast cancer. Williams (2002) states: “Socioeconomic status is a central determinant of racial/ethnic disparities in health, but several other factors, including medical care, geographic location, migration and acculturation, racism, and exposure to stress and resources also play a role. There is a need for renewed attention to monitoring, understanding, and actively seeking to eliminate racial/ethnic disparities in health" (p. 588).

Chapter 3 Methodology

Research Design

Qualitative research synthesis.

The process of qualitative research synthesis has been chosen as the research design for this study due to the comprehensive, objective, replicable and systematic nature of these reviews. Qualitative research synthesis is considered to be more descriptive of the integrative and interpretive nature of this study (Sandelowski & Barroso, 2007), and has been adopted by this author as the primary descriptor for this study. However, as a dynamic and emerging methodology, many studies, particularly those published prior to 2008 refer to this same process using the term Systematic Review. Therefore, within this study, the terms Qualitative Systematic Review and Systematic Review are considered to be interchangeable. "The rationale for such reviews is well established. Health care providers, researchers, and policy makers are inundated with unmanageable amounts of information; they need systematic reviews to efficiently integrate existing information and provide data for rational decision making" (Mulrow), 1994, p. 597).

As stated in Fisher, Qureshi, Hardyman and Homewood (2006), Systematic Reviews have been used extensively in the past, in quantitative research, to provide a quick reference for busy providers of healthcare services who are interested in developing practice methods and intervention methods, based on these reviews. Qualitative research syntheses are now emerging as an excellent source that provides solid information for practice, interventions *and* policy. It decreases researcher bias because all available and appropriate studies are utilized, as are explicit and rigorous methods of analysis. Evidence supports the use of qualitative research synthesis as a viable format for PhD dissertation requirements, specifically in the area of healthcare policy development (Akir, 2006; Douglas, 2007; Perry & Hammond, 2002; Sambunjak & Puljak, 2010).

According to Cook, Mulrow and Haynes (1997), the necessary components of a qualitative research synthesis include: 1) a defined question, 2) pre-defined inclusion and exclusion criteria, 3) a replicable search strategy for evidential sources, 4) critical evaluation of selected research, 5) qualitative, or quantitative and mixed methods data synthesis, and 6) conclusions based on the included evidence. The specific boundaries utilized in a qualitative research synthesis of pre-defined inclusion and exclusion criteria both reduce the potential for investigator bias and support the positivistic nature of the review because it emphasizes the scientific and objective nature of the study (Weed, 2005). However, Weed also states that the objective of an interpretive approach inherent in a qualitative research synthesis, may result in a modification of the inclusion / exclusion criteria as the study data is reviewed. This is supported by Sandelowski and Barroso (2007), who discuss the iterative nature of the discovery process and the likelihood of change to the inclusion / exclusion criteria as an understanding of the research is further revealed. Objectivity is enhanced through the use of various checklists to ensure the critical appraisal of the selected research intended for this study (Barbour and Barbour, 2003; Popay, Williams and Rogers, 1998).

The methodology chosen for this study is an interpretive metasynthesis of secondary qualitative data. Secondary data is less expensive, easier to acquire, and due to the process of critical appraisal, the issues of reliability and integrity are greatly mitigated (Weed, 2005). The process of interpretive metasynthesis involves the re-presentation of secondary data that is, in turn, based on the primary data (research findings) gathered in the original studies (Sandalowski & Barrroso, 2007). The challenges of utilizing qualitative data for a research synthesis include the scarcity of developed methods for review when compared to randomized control trials which were the primary basis of Systematic Reviews at their inception. Additionally, the lack of generalizabilty of qualitative data, which is viewed as specific to a particular time, context and participant group is another challenge. However, the case has been made regarding the opportunity for the synthesis of qualitative research to inform policy and practice due to the comprehensive search methodology of relevant studies and the richness of the data provided. In addition, policy makers struggle with the significant quantities of data and benefit from the syntheses of findings from several research sources available in a qualitative research synthesis (Thomas and Harden, 2008; Weed, 2005). Furthermore, an understanding of the process of qualitative research synthesis would be a valuable addition to the social work curriculum in that it provides a rigorous methodology that exposes the student to assessment and interpretive tools for qualitative research.

Qualitative description and researcher role.

Crabtree and Miller (1999) state that qualitative description "… explores meanings, variations and perceptual experiences of phenomena and will often seek to capture their holistic or interconnected nature" (p. 6). As a qualitative study, this is considered an interpretivist view. The research paradigm that most closely corresponds with this study is social constructivism. In this exploratory descriptive study, the constructivist view allows for the individuals to construct the meaning of their survivorship and how those meanings were negotiated culturally, socially, and historically by the world around them. The meanings of the breast cancer survivors' experiences lead to a complexity of views with many categories as opposed to a narrow view that quantitative methods would provide. The cultural, social, and historical background of individuals forms their views and meanings and the investigator inductively develops a pattern of meanings that may lead to an empirically grounded conceptualization (Creswell, 2007).

The interpretation of data by the researcher, albeit analysis of secondary data, is seen through the lens of the researcher's own background and beliefs. Therefore, the researcher acknowledges bias and deals with it through honest reflection throughout the study (Creswell, 2007). I know that as a white, middle class, educated woman, I do not represent all breast cancer survivors, especially those from different cultural and socioeconomic backgrounds. Understanding the meaning of survivorship across cultural, social, and historical boundaries is important to make sure that the Eurocentric, white, middle class view point does not translate into policy and practice outcomes that would presume to be useful for all breast cancer survivors. Alternately, as a survivor of breast cancer who has contact with other survivors of breast cancer, I have both a personal understanding and experience of the issues related to survivorship, as well as anecdotal input from other breast cancer survivors that go beyond a white middle class and Eurocentric view. Creswell (2003) discusses the researcher's role and urges "…inquirers explicitly identify their biases, values and personal interests about the research topic and process" (p184). Grinnell (2001). adds the importance of understanding the context of the setting of the study.

However, many of the issues are based on primary research processes that are not included in this study. These include Backyard research (studying the researcher's own organization, or friends, or immediate work setting) as described by Glesne & Franklin (cited in Creswell, 2003, p. 184), Institutional Review Board approval, approval of gatekeepers for entry into the setting; data collection procedures, settings and storage. The structure of a qualitative research synthesis, including defined inclusion and exclusion criteria, and quality appraisal of data, serves to somewhat mitigate this potential bias.

As noted by Denzin, "[I]nterpretive research begins and ends with the biography and self of the researcher" (1989, p. 12). This researcher has already expressed an awareness of preconceptions and bias as a breast cancer survivor. This can be an advantage for framing the study, and for choosing the criteria for inclusion and exclusion of articles. That is true *if* there are checks and balances built into the research process, such as Crabtree and Miller's recommendation that an inventory of the researcher's "past incidents, associations, and assumptions related to the research area" be conducted and shared within the research team (1999, p. 95). I have discussed issues of possible bias and how to best address those with my dissertation committee.

I have been journaling thoughts and feelings during the preparation for, conduct and writing of the research. The contents of the journal have been discussed with a trusted and experienced researcher, who has acted as a mirror, reflecting back thoughts and feelings by employing her insights of the journal for discussion. This process has assisted in recognizing and controlling any preconceptions and biases. The focus has been to allow the data gathered from the findings of the voices of the breast cancer survivors to form the emergent theory, not to confirm or disconfirm personal experience of survival.

While I must consider the above concepts to address issues of bias as related to this researcher, the content that is under examination and exploration is not the raw interviews or primary data but rather the content, methods and reported or articulated results that are found in the selected articles under review. This is a major consideration and, accordingly, the issues of bias and / or the quality of the research methodology of the authors of the primary research must also be included in the qualitative research synthesis assessment process (Sandelowski & Barroso, 2007).

Grounded Theory

A grounded theory approach provided a basis for investigation of the issues related to the questions and for constructing a theoretical model. This approach starts with an idea from an observation, not with a-priori theory, that tries to fit the phenomena to the theory. This grounded theory approach allows for the theory to be constructed by those that are living the experience and is grounded in the data that the participants provide (Corbin & Strauss, 1990). Grounded theory provided a method for exploring the realities and meaning of surviving breast cancer within the context of various frameworks and ideologies of health and illness, gender and roles, as well as culture.

Glaser and Strauss (1967) refer to a comparative analysis approach accomplished by comparing groups and subgroups, their differences and similarities, and then revisiting this comparison with other groups and subgroups until themes and patterns begin to emerge. "In discovering theory, one generates conceptual categories or their properties from evidence, then the evidence from which the category emerged is used to illustrate the concept" (p. 23). As an iterative process that takes the researcher wherever the data, coding results, and analysis goes, new directions are considered part of the process. This process continues until saturation is reached. "In trying to reach saturation he [sic] maximizes differences in his [sic] groups in order to maximize the varieties of data bearing on the category, and thereby develops as many diverse properties of the category as possible" (p. 62). In this research paper, the central phenomenon under study was the meaning and the experience of women surviving breast cancer across cultures within the various frameworks and ideologies of the individual’s life and world-view (Creswell, 2003). Of course, all women experienced the trauma of being diagnosed with breast cancer, a life threatening and life changing illness, but significant differences were exposed.

Initially, broader categories were used, but it became clear that six factors, along with culture, influenced the intensity and direction of that meaning. Emotional; financial; physical; psychological; social; and spiritual factors were necessary to uncover the nuances of the meaning of breast cancer survival. Upon continuing the comparative process; additional elements emerged of women's roles and identities, which became a central concept of the study.

Research Protocol

This study was a qualitative research synthesis of available literature utilizing the combined guidance of the Forum: Qualitative Research (Weed, 2005) and the Cochrane Collaboration (Higgins & Green, 2005). A protocol was established for the study plan consistent with the guidelines defined in Schlosser (2007). As stated previously in the introduction, the purpose of the study was to appraise, synthesize and interpret the findings of the existing literature and research that explores the meaning, value, and emotional experience of surviving breast cancer, and to discover if and how it relates to breast cancer survival across cultures. The following cultures were included: African American, Asian American, Latina American and Caucasian American. Criteria for inclusion and exclusion of studies were defined, including types of studies, types of participants and search strategies for identification of studies (see Table 1: Inclusion / Exclusion Criteria) and (Figure 1: Search Parameters).

Table 1: Inclusion / Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
African American, Asian, Latina, White American	
WSBC, Stage 0 thru III inclusive, 1yr beyond treatment and adjuvant therapy. Currently cancer free.	Stage IV Cancer Survivors; WSBC receiving adjuvant therapy,
No history of prior cancer.	
WSBC age 40 to 65 yrs inclusive.	
Qualitative Studies and Mixed Method Studies	
Studies within the past 10 years	
Studies of American WSBC	

The search was conducted in the following electronic databases: PubMed Central (NCBI), Web of Science, Medline, PsycINFO, EMBASE, CINAHL, SocINDEX, and the Cochrane Controlled Trials Register. Search parameters for the major databases are included in Figure 1.

Figure 1: Search Parameters

2/15/11 Pubmed search - 1507
(breast cancer[Title/Abstract] AND (full text[sb] AND Humans[Mesh] AND Female[MeSH Terms] AND (Meta-Analysis[ptyp] OR Practice Guideline[ptyp] OR Review[ptyp] OR Case Reports[ptyp] OR Classical Article[ptyp] OR Clinical Conference[ptyp] OR Comparative Study[ptyp] OR English Abstract[ptyp] OR Government Publications[ptyp] OR Guideline[ptyp] OR Interview[ptyp] OR Journal Article[ptyp] OR Lectures[ptyp] OR Research Support, N I H, Extramural[ptyp] OR Research Support, N I H, Intramural[ptyp] OR Research Support, Non U S Gov't[ptyp] OR Research Support, U.S. Government[ptyp] OR Research Support, U S Gov't, Non P H S[ptyp] OR Research Support, U S Gov't, P H S[ptyp]) AND English[lang] AND (jsubsetn[text] OR systematic[sb]) AND middle age[MeSH] AND "last 10 years"[PDat]))) OR breast cancer surviv*[Title/Abstract]) NOT europ*[Title/Abstract]) NOT austral*[Title/Abstract]) NOT polymorphism[Title/Abstract]) NOT metast*[Title/Abstract]) NOT myeloma[Title/Abstract]) NOT randomized[Title/Abstract]) NOT RCT[Title/Abstract]) NOT neoplasm[Title/Abstract]) NOT BRCA*[Title/Abstract]) NOT quantit*[Title/Abstract]) *[Title/Abstract])) NOT adjuvant[Title]) NOT chemo*[Title]) NOT radio*[Title]) NOT radiation[Title]) NOT lymphoed*[Title]) NOT cardi*[Title]) NOT surg*[Title]) NOT lymph*[Title])) NOT gene*[Title]) NOT mammography[Title]) NOT insulin[Title]) NOT hormone[Title]) NOT zealand[Title])) NOT estrogen[Title]) NOT randomi*[Title]) NOT mammograph*[Title]) NOT mastectomy[Title]) NOT UK[Title]) NOT hormon*[Title]) NOT randomi*[Title/Abstract])) NOT chemo*[Title]

2/15/11 Web of Science - 374
#33 NOT TS=(diagno*) NOT TS=(recurr*) NOT TS=(metast*) NOT TS=(randomi*) AND Language=(English) AND Document Type=(Article)
#31 NOT TS=(diab*) AND Language=(English) AND Document Type=(Article)
#29 NOT TI=(neoplasm) NOT TS=(BRCA*) NOT TS=(quantitat*) AND Language=(English) AND Document Type=(Article)
Refined by: [excluding] Subject Areas=(BIOCHEMISTRY & MOLECULAR BIOLOGY OR NUTRITION & DIETETICS OR OBSTETRICS & GYNECOLOGY)
#28 AND TS=surviv* AND Language=(English) AND Document Type=(Article)
Title=("breast cancer") NOT Title=(adjuvant) NOT Title=(chemo*) NOT Title=(recurrance) NOT Title=(randomi*) NOT Title=(mastectomy) NOT Title=(cardi*) NOT Title=(surg*) NOT Title=(estrogen) NOT Title=(gene*) NOT Title=(mammograph*) NOT Title=(radiation) NOT Title=(lymph*) NOT Title=(insulin*) NOT Title=(hormon*) NOT Title=(polymorphism) NOT Title=(metast*) NOT Title=(myeloma)
Databases=SCI-EXPANDED, SSCI, A&HCI Timespan=2001-2011
2/15/11 PsycINFO - 93
AB "BREAST CANCER" and AB SURVIVOR not AB RANDOMI* not AB QUANTIT* not TI EUROP* not TI METAST* not TI CHEMO* not TI RADI* not TI LYMPH* not TI UK not TI AUSTRAL* Limiters - Linked Full Text; Published Date from: 20010101-20111231; Peer Reviewed Narrow by SubjectAge: - Middle Age (40-64 yrs) Search modes - Find all my search terms
2/15/11 CINAHL with Full Text – 13
AB "BREAST CANCER" and AB SURVIVOR not AB RANDOMI* not AB QUANTIT* not TI EUROP* not TI METAST* not TI CHEMO* not TI RADI* not TI LYMPH* not TI UK not TI AUSTRAL* Limiters - Linked Full Text; Published Date from: 20010101-20111231; Peer Reviewed Narrow by SubjectAge: - Middle Age (40-64 yrs) Search modes - Find all my search terms

The search did not include grey literature, i.e. relevant government and non-government reports, conference papers and proceedings, thesis and dissertations, research and technical reports, and ongoing research. The variety of selection of electronic databases is believed to be sufficient to exclude publication or database bias. A secondary hand search of bibliographies of selected articles was performed to expand the search.

The initial search was refined to include search terms such as (1) Breast Cancer, (2) Survivor, (3) Thoughts, (4) Thinking, (5) African American Women, (6) American Latina

Women, (7) Asian American Women, (8) White American Women, (9) Ruminations, (10) Systematic Review, (11) Qualitative, (12) Worry, (13) Fear. These terms were used in combinations consistent with the inclusion criteria of the study. Specific constraints were included regarding Geographic (United States) and Temporal (within the last 10 years) factors in order to target studies consistent with the unique characteristics of the medical delivery systems within the United States, and to ensure currency of data. There were no linguistic constraints imposed.

Inclusion and exclusion of studies

Studies considered eligible for inclusion into this review were qualitative or mixed method in nature, and present primary research of the health quality of life of women survivors of breast cancer. Women included in this review (1) had a past diagnosis of one incidence of breast cancer (stage 0, I, II, or III), (2) were at least one year past primary cancer treatment, including surgery, radiation or chemotherapy, (3) were cancer free at the time of this segment of the study, (4) had no history of any other cancer, and (5) were between the ages of 40 and 65 years of age. Populations considered for this study included African American, Asian American, Latina American and White American women survivors of breast cancer. Specifically excluded from the study were Stage IV Cancer Survivors, survivors with any recurrence of cancer and those receiving adjuvant therapies.

Rationale for Exclusion Criteria

One incidence of cancer was considered relevant, in that research demonstrates that a cancer recurrence produces a different dynamic than one occurrence. Cancer recurrence is typically associated with an increased level of distress, being perceived as the failure of earlier cancer treatments (Warren, M., 2009; Aranda, Schofield, Weih, Yates, Milne, Faulkner & Voudouris, 2005; Sanson-Fisher, Girgis & Boyes, 2000; Vilhaur, 2008).

Stage IV cancer was not included, since 93% of breast cancer diagnoses in women are at Stages 0 through 3 (Altekruse, et al., 2010), and the threat of death is three to five times higher with Stage IV (Imaginis, 2010).

Breast cancer survivors who were not one year past primary cancer treatment were excluded because end of treatment has been mentioned as a shift in a sense of safety in being monitored (Ganz, et al., 2004; Costanzo, 2006). The end of treatment signals both relief and anxiety: relief, because another milestone in survival has been reached, and anxiety, because medical monitoring is greatly reduced. This is seen as a double-edged sword because the shift in monitoring can, at once, produce either or both, relief or anxiety (Gaudine, 2003).

Subsequent to the review of the abstracts of the articles selected via the initial search, the criteria for inclusion of studies according to age were expanded from 40 to 65 years inclusive, to 30 to 85 years inclusive. Though the age range is wider than initially considered, due to the high level of anxiety in younger and older breast cancer survivors (Thewes, Butow, Girgis & Pendlebury, 2004; Porter, 2006), it allowed for a greater selection of articles and the added cultural component of age. This modification of inclusion / exclusion criteria is consistent with the interpretive approach of a qualitative research synthesis as previously discussed (Weed, 2005; Sandelowski & Barroso, 2007). The younger breast cancer survivors experience anxiety because the cancer is usually more serious when younger and may affect fertility, sexual functioning, finding a mate, etc. The older survivors experience anxiety because as people age, other illnesses present themselves with symptoms that may seem like cancer has returned, and the co-occurring long-term effects of cancer treatment also reduces health and wellness (Thewes, et al, 2004).

Methods of the Research Synthesis

Data extraction.

A data extraction form was utilized to aid in the consistent gathering of data from the retrieved articles (see Table 2).

Table 2: Data Extraction Form

Study Demographics	
First Author	
Pub. Date	
Title	
Affiliation(s)	
Funding Source	
Period of Data Collection	
Location of Study	
Publication Type/Name	
Research Problem	
Research Purpose / Objective	
Orientation towards Target Phenomenon	
Orientation Towards Inquiry	
Method	
Sampling Strat. / Technique	
Sample Size / Composition	
Ethnic composition / focus	
Data Collection Techniques / Sources	
Data Mgmt / Analysis Techniques	
Findings	
Logic & Form of Findings	
Type / Classification	
Summary of Findings	
Discussion/Implications	
Stated Study Limitations	

An initial screening of the 1,946 retrieved articles was performed based upon the article abstracts. Those article abstracts that satisfied the initial screening against the modified inclusion criteria stated above (105) were subjected to a full text review. This resulted in a total of 49 articles, whose data was subsequently summarized on a data extraction form for use in the quality appraisal.

Quality appraisal.

The 49 articles selected for quality appraisal were assessed to establish relevance to the research questions and methodological validity. The appraisal was documented on a standardized appraisal instrument consistent with the Joanna Briggs Institute System for the Unified Management, Assessment and Review of Information package see Figure 2.. This appraisal checklist included a number of questions that formed an initial framework for evaluation and potential inclusion:

Figure 2: JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

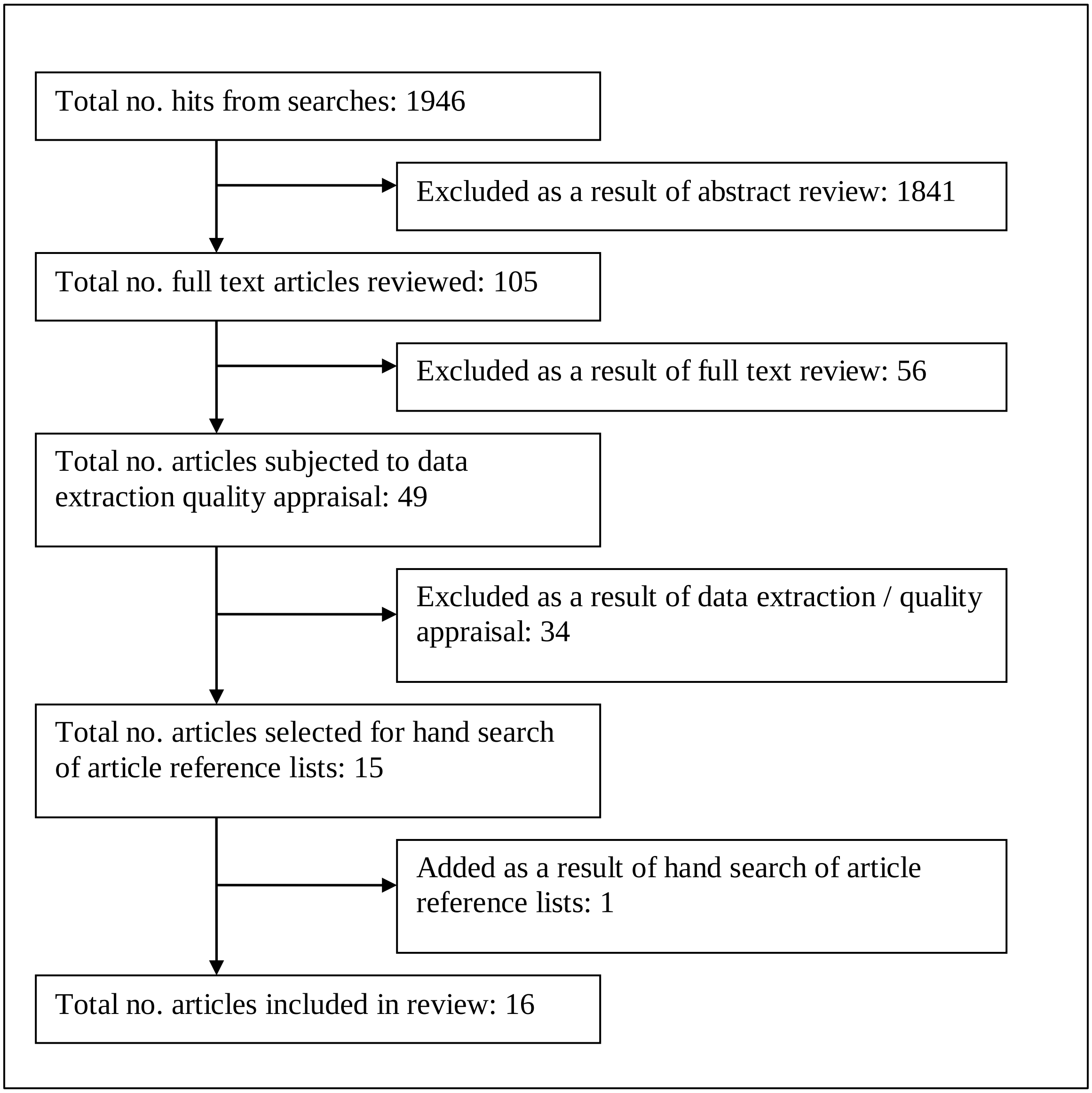
Reviewer ____________________________________ Date ______________
Author ______________________________________ Year ______________
Record Number _________

		Yes	**No**	**Unclear**
1.	Is the study relevant to the central concept of the hidden nature of WSBC survival?	☐	☐	☐
2	Is the study consistent with the inclusion criteria for primary research?	☐	☐	☐
3	Is the research question clear? Is there an adequate identification of potential researcher bias?	☐	☐	☐
4	Is the design methodology appropriate to the research question?	☐	☐	☐
5	Is there a clear and discoverable process for data collection and analysis?	☐	☐	☐
6	Additional appraisal question.	☐	☐	☐
7	Additional appraisal question.	☐	☐	☐

The criteria for appraisal included a combination of unprompted judgment, or reliance on the expertise of the researcher to judge the quality of the source, and a modification of the Critical Appraisal Skills Programme Tool for appraising qualitative research, as described in Dixon-Woods, Sutton, Shaw, Miller, Smith, Young, Bonas, Booth and Jones (2007) methodological appraisal for research supporting qualitative research syntheses.

As a result of the quality appraisal process, 34 articles were excluded resulting in a total of 15. A subsequent hand search of the 15 articles' reference lists resulted in the addition of one article, leaving a total of 16 articles utilized in this study. A graphical presentation of the results of the iterative search process is provided (see Figure 3).

Figure 3: Diagram of Search Outcomes



Synthesis.

In this section, I move from the explication of qualitative research synthesis to a description of how the synthesis itself was applied in this study. According to Sandelowski and Barroso in the "Handbook for Synthesizing Qualitative Research" (2007),

> Qualitative metasynthesis is an interpretive integration of qualitative findings that are themselves interpretive synthesis of data, including the phenomenologies, ethnographies, grounded theories, and other coherent descriptions or explanations of phenomena, events or cases that are the hallmark findings of qualitative research. Metasyntheses are integrations that are more than the sum of parts in that they offer novel interpretations of findings that are the result of interpretive transformations far removed from these findings as given in research reports (p.18).

Sandelowski and Barroso are clear that in qualitative metasynthesis, the findings must be faithful to each report while reframing, reorganizing and reinterpreting each to create a "fully integrated description of a target event or experience" (p.18) which requires interpretive logic, not mere reporting.

The synthesis of data was accomplished through a process of inductive analysis, and comparing and contrasting the study findings to establish a pattern of recurring themes as discussed in the prior section on Grounded Theory development. A taxonomy of findings was developed that linked these findings to developed themes. These themes were further categorized based on similarity of meaning related to the cultures under study. Multiple iterations of the syntheses were performed thorough a process of constant comparison that refined the categories and themes, resulting in a final, delimited grounded theory. A narrative synthesis of these themes is part of the presentation of the data. The coding process was further supported via computer assisted qualitative data analysis software coding using the Qualrus Intelligent Qualitative Analysis Program.

Chapter 4 Results

Introduction

The findings of this qualitative research synthesis were gathered from the sixteen articles that met the criteria for selection and the quality appraisal as described previously. It is important to note that, as prescribed by the process for a qualitative research synthesis (Sandalowski and Barroso, 2007), the findings used for this synthesis are taken from the findings of the selected articles. This is to differentiate these findings from the data collected from the research participants by the primary researchers, which were subsequently used to develop their findings.

Demographics

The sixteen selected studies varied as to demographic construction of participants. As indicated in Table 3 a total of 490 participants were involved in the primary studies. Of that 490, 37% were African American, 7% were Asian American, 39% were Caucasian and 10% were Latina. While the greatest percentage of participants reflect African American and Caucasian ethnicity, it should be noted that the responses provided by the Asian American and Latina participants across related studies were consistent.

Table 3: Demographics of Selected Studies - Ethnicity

Study ID	**1st Author**	**Ethnicity**					
		African American	Asian American	Caucasian	Latina	Non-Specified	Total
1	Allen	7	0	38	2	0	47
2	Ashing-Giwa	24	34	18	26	0	102
3	Buki	0	0	0	18	0	18
4	Capiello	0	1	18	1		20
5	Gallia	11	0	0	0	0	11
6	Gonzales	0	0	8	0	0	8
7	Hamilton	15	0	0	0	0	15
8	Henderson	66	0	0	0	0	66
9	Kantsiper	5	0	16	0	0	21
10	Kooken	21	0	0	0	0	21
11	Rosedale (2009)	3	0	10	0	0	13
12	Rosedale (2010)	0	0	0	0	13	13
13	Roundtree	4	0	28	1	0	33
14	Sulik	3	0	54	0	3	60
15	Ucok	0	0	0	0	18	18
16	Wilmoth	24	0	0	0	0	24
	Total	**183**	**35**	**190**	**48**	**34**	**490**

The ages of the research participants ranged from 30 to 86 years. The selected articles did not provide data sufficient to provide a mean distribution across all studies, however, based upon a weighted average of studies that did provide mean ages, it was determined that the mean age of the participants was 55 (see Table 4). While there were some studies that included participants at the lower age range (30-40), there were no studies that specifically focused on either younger or older breast cancer survivors. The findings that specifically identified young (typically pre-menopausal) and older (greater than 60 years) breast cancer survivors were included, and identified as such.

Table 4: Demographics of Selected Studies - Age

Study ID	1st Author	Age	
		Age Range	Mean (years)
1	Allen	35-86	57
2	Ashing-Giwa	31-81	55
3	Buki	35-67	51
4	Capiello	33-80	52
5	Gallia	40-84	Unknown
6	Gonzales	44-71	59
7	Hamilton	42-87	60
8	Henderson	35-76	52
9	Kantsiper	Unknown	Unknown
10	Kooken	38-78	59
11	Rosedale (2009)	33-74	Unknown
12	Rosedale (2010)	33-74	Unknown
13	Roundtree	42-75	60
14	Sulik	31-79	54
15	Ucok	37-74	53
16	Wilmoth	30-75	Unknown
	Total	**30-86**	**55 ***

*Weighted average of known mean ages.

Characteristics of the Studies

The sixteen selected articles reflected variations in methodology, orientation, logic and form of findings and type or classification. These characteristics are identified in Table 5. All but one of the studies were qualitative in nature, with one being mixed-method. This is consistent with the pre-determined selection criteria. The stated orientations of the studies included grounded theory development, exploratory/ pilot reviews, social constructionist perspectives, ethnographic analysis, and empirical, interpretive and descriptive phenomenological analyses. Of the sixteen selected studies, the largest group (five) explicitly identified the use of grounded theory for interpretation. It was important to identify the researchers' orientation in order to both understand the perspective of the researchers as they interpret the findings and to assist in classifying the type of study. The classification of studies for a qualitative research synthesis ranges along a continuum from those studies that are closest to the data to those that are farthest from the data, as regards interpretation of the data. Those studies that are explanatory in nature, with the highest degree of interpretive explanation, are most useful for a metasynthesis (Sandalowski and Barroso, 2007). Nine of the selected studies included interpretive explanations, six were thematic descriptions or surveys, and one was a topical survey.

Table 5: Characteristics of Selected Studies

Study ID	1st Author	Study Characteristics			
		Method	**Stated Orientation**	**Logic & Form of Findings**	**Type/ Classification**
1	Allen	Qualitative	Constant Comp. Analysis / Grounded Theory	Thematic construction with quantitative identification of positive, negative & neutral comments.	Conceptual thematic description
2	Ashing-Giwa	Qualitative	Comparative analysis / Exploratory	Thematic construction, tabulated matrix for comparisons	Conceptual thematic description with interpretive explanations
3	Buki	Qualitative	Grounded Theory	Thematic construction / relevancy to survivorship stages	Conceptual, thematic and temporal description.
4	Capiello	Qualitative	Exploratory review of information & support needs.	Narrative description of findings grouped in pre-determined categories.	Topical Description
5	Gallia	Qualitative	Social constructionist based upon McAdams' life story analysis framework.	Narrative form assigned to themes centered on redemption.	Conceptual and thematic descriptions.
6	Gonzales	Qualitative	Ethnographic	Thematic construction based on a polyvocal representation of the acute phase of survival	Thematic description with some interpretive explanations.
7	Hamilton	Qualitative	Grounded Theory	Quantitative description assigned to discovered themes.	Topical survey with some interpretive explanations.
8	Henderson	Mixed Method	Exploratory review of coping strategies.	Narrative description of discovered themes enhanced by quantitative analysis of demographic data.	Thematic survey.

Study ID	**1st Author**	**Study Characteristics**			
		Method	**Stated Orientation**	**Logic & Form of Findings**	**Type/ Classification**
9	Kantsiper	Qualitative	Thematic analysis	Narrative description assigned to discovered themes.	Thematic survey.
10	Kooken	Qualitative	Empirical and interpretive phenomenological analysis.	Narrative form as a polyvocal representation.	Interpretive explanation.
11	Rosedale (2009)	Qualitative	Descriptive phenomenological study.	Narrative form describing the essence of the experience of survivor loneliness.	Conceptual description with interpretive explanations.
12	Rosedale (2010)	Qualitative	Secondary qualitative analysis.	Narrative form assigned to developed themes.	Thematic description with interpretive explanations.
13	Roundtree	Qualitative	Grounded Theory	Narrative form assigned to developed themes.	Thematic description with interpretive explanations.
14	Sulik	Qualitative	Grounded Theory	Narrative form assigned to developed themes.	Thematic description with interpretive explanations.
15	Ucok	Qualitative	Social Interactionist, Ethnographic	Narrative form assigned to pre-determined themes.	Thematic description with interpretive explanations.
16	Wilmoth	Qualitative	Pilot Study	Narrative form assigned to developed themes.	Thematic survey.

Themes of the Findings

The themes, or issues, identified in the findings are summarized in Table 6: Summary of Identified Themes / Narrative Issues. . Some of the themes overlapped between studies, and some were unique to a study. The primary themes that recurred among the sixteen selected articles were:

1. Positive reframing: coping strategies, gaining insight and control, empowerment, adaptation, reflective assessment, self-agency.
2. Psychological, emotional and physical impacts of breast cancer: fear of recurrence, distress, loneliness, well-being, fatigue, ongoing symptoms.
3. Body image: effect on intimacy, feminine beauty, markedness, effects on social interactions
4. Loss of self: return to normalcy, inauthentic mirroring, withholding truth, gender norms, negotiating identity.
5. Social Support: communion, meaningful connections, spirituality, information, cares issues.
6. Healthcare system: physician relationship, reassurance from specialty care and surveillance, socialized silence, insensitivity of healthcare providers, distrust.

The findings gleaned from the studies are summarized in Appendix C: Data Extraction Summaries.

Table 6: Summary of Identified Themes / Narrative Issues

ID	1st Author	Ethnic Composition	Identified Themes / Narrative Issues
1	Allen	African American, Caucasian, Latina	• Positive life changes as a result of the cancer experience • Fear of recurrence • Emotional distress • Losses associated with the end of treatment • Difficulty returning to "normal life"
2	Ashing-Giwa	African American, Asian American, Caucasian, Latina	• Factors helping recovery, coping • Control over illness, participation in treatment • Feelings about body, intimate relationships • Relationship with doctor • Factors affecting quality of treatment • Overall stress/effect of breast cancer • Work, career issues
3	Buki	Latina	• Acute Stage o Perceptions of psychological well being o Impact of diagnosis on well-being o Need for social support • Reentry Stage o Perceptions of psychological well being o Impact of treatment on well-being o Need for social support o New attitude development • Long-Term Survivorship o Perceptions of psychological well being o Need for social support o New attitude development
4	Capiello	Asian American, Caucasian, Latina	• Physical distress • Psychological distress • Informational needs • Challenges in the year after breast cancer treatment
5	Gallia	African American	• Agency: gaining insight, control, power, accomplishment or empowerment • Communion: experiencing love, friendship, reciprocal communication, caring or togetherness • Imagoes: idealized self-representations functioning as characters in the narratives
6	Gonzales	Caucasian	• Assumption of an Adaptive Position • Need for Tangible Evidence of Love and Support • Need for Something More: Meaningful connections with others, spiritual connections.

ID	1st Author	Ethnic Composition	Identified Themes / Narrative Issues
7	Hamilton	African American	• Emotional support • Instrumental support • Informational support
8	Henderson	African American	• Coping Strategies o Relying on prayer o Avoiding negative people o Social support o Positive attitude o Will to live
9	Kantsiper	African American, Caucasian	• Survivors derive reassurance from specialty care and surveillance • Survivors' perceptions of primary care providers role in care • Unmet needs of survivors • Use of cancer survivorship care plans • Effect of historical influences and spirituality upon African American survivors
10	Kooken	African American	• The Beginning (diagnosis, vigilance, concerns for feminine beauty) • No News in BAD NEWS (treatment as the long wait, patients as invisible objects) • A Psalm of Survival (faith overcoming adversity) • The Pink Ribbon Shield (insensitivity of healthcare system) • ERAC – Backwards CARE (distrust of healthcare system) • Fatigue … Beyond Tiredness (side effects of treatment) • I've Been Through Something (survival as a process of reflective assessment)
11	Rosedale (2009)	African American, Caucasian	• Emerging Consciousness (loneliness) • Transcending Time (ongoing nature) • Misunderstanding (life changing nature) • Inauthentic Mirroring (pressures to act like a hero) • Fragile Vital Connections (heightened existential awareness) • Withholding Truth (reluctance to reveal oneself)
12	Rosedale (2010)	Unspecified	• Living with Lingering Symptoms • Confronting Unexpected Situations • Losing Pre-Cancer Being • Feeling Like a Has-Been

ID	1st Author	Ethnic Composition	Identified Themes / Narrative Issues
13	Roundtree	African American, Caucasian, Latina	• Personal Experiences ○ Facing barriers to screening ○ Feeling in limbo in the healthcare system ○ Communicating with providers ○ Determining in current healthcare problems are cancer related • Personal Attitudes ○ Perception of survivorship ○ Recurrence concerns ○ Retrospective self-perception ○ Self-agency • Social Influences ○ Modeling behaviors of others ○ Weighing effects on family ○ Weighing the social effects of care
14	Sulik	African American, Caucasian	• Breaking Gender Norms: ("I've become more of a 'me, me' person") • Negotiating Identity: ("I'm very gray now about who I really am") • Re-inscribing Gender Norms: ("Giving back")
15	Ucok	Unspecified	• Bodily Appearance and Social Interaction ○ Markedness and gendered bodily appearance ○ Responses of others (real and anticipated) ○ Effects of mastectomy on social interaction • Bodily Appearance and Self ○ Hair loss is also a loss of self ○ Interdependence of physical bodies and self ○ Disruption of identity related tobody image and social interaction ○ Effects of mastectomy on one's self
16	Wilmoth	African American	• Body appearance • Social support • Health activism • Menopause • Learning to live with a chronic illness

Chapter 5 Discussion

Grounded theory progression.

The findings identified within the sixteen selected articles formed the basis for development of a grounded theory related to breast cancer survival as the focus of this study. Through the process of discursive reading of the articles, iterative coding of the article segments against apriori and developed criteria (codes), (see Appendix A: Codes and Links), and constant targeted comparison (see Table 7), a theory emerged that, in its final form, was related to the work of developing a new survivor identity … “survivor work”. The initial metasynthesis of findings was enacted using a process of discursive reading of the findings and visual displays of the summarized elements utilizing a series of affinity charts to cluster the qualitative data and represent them in a storyboard fashion. The incorporation of affinity charting, while typically utilized as a process to achieve group consensus, was nevertheless helpful in revealing the interrelationship of findings and the resultant themes.

Table 7: Constant Targeted Comparison Guideline

LIFE CHANGING IMPACT OF BC	
Life before diagnosis • Sense of safety • Wellness • Status quo • Normalcy • Living / life is taken for granted • Caregiver	Life after diagnosis • life threatened (physically) • care receiver (person in need of support) • has both positive and negative meaning ○ negative ▪ ongoing multi-factor impact ▪ misunderstood ▪ loneliness ▪ fear ▪ uncertainty ▪ loss of innocence ○ positive ▪ re-appraisal ▪ altruism ▪ lifestyle improvements
IDENTITY (wife, mother, family member, friend, neighbor)	
Others expectations / perceptions of the WBCS • during diagnosis & treatment phase vs post treatment phases • want to see things as before (normal) • Let's celebrate! … It's over. • WSBC need less support. • To see WSBC act like a hero. • Be positive (conceal fears and symptoms)	Physical, emotional and psychological lived experience of the WSBC • Inner struggle with shift to focus on self (individualistic / self-interested) • I am not who I was before. I am a WSBC. • Guilt about burdening others. • During diagnosis & treatment phase ○ Wanting to survive • During post treatment phases ○ Impact of change in body image ○ Long term physical, psychological and emotional impacts (pain, fatigue, stamina, loss of memory, cognitive function, etc.) • The 'silenced' BCS ○ Concealed true feelings ○ Silent hero ○ Need to be strong for others ○ Negative relationships weakened by illness ○ Stigma & disclosure (hidden as a child, uncomfortable to others)
WOMANHOOD	
A sexual, nurturing woman • Sexual being • Caregiving and nurturing Mother • Supportive and loving wife	A 'violated' woman • Impact of feminine beauty on male relationships • Effects of adjuvant treatment on sexual function • Increased sense of vulnerability • Internal impact of body image on male relationships • Role reversal (caregiver to care receiver) • Shift from other centered to self-centered (guilt producing)

Three taxonomic organizations were developed over the course of the study. The progression of theory development is outlined in Table 8.The preliminary categories focused on the internal and external factors that impact the experience of the breast cancer survivor. In the second level, the categories were transformed into the various identity roles played by the survivor, and how those roles were impacted by the previously identified internal and external factors. The final level ended with a delimited theory that describes the relationship between emotion work, grief work and identity work as a process to renegotiate a new survivor identity for the breast cancer survivor.

Table 8: Grounded Theory Progression for Categories – Taxonomy of Findings

Level 1	Level 2	Level 3
Preliminary Categories	Transformed Categories	Delimited Theory
Internal / External Factors	**Identity Roles**	**Survivor Work =**
Emotional Factor (effects, or is effected by) Expectations of Self & Others Fear of Recurrence Giving Back Guilt Related to Becoming a Burden to Others Healthcare System / HCP Sensitivity Isolation Loss of Control Loss of Friendships Mindfulness Socialized Silence Stigma & Disclosure Thoughts Urgency of Life ***Financial Factor (effects, or is effected by)*** Healthcare System Information Loss of Control Social Support Thoughts Uncertainty ***Physical Factor (effects, or is effected by)*** Body Image Feminine Beauty Stigma & Disclosure Sexual Function Loss of Friendships Thoughts ***Psychological Factor (effects, or is***	***Person Changed by BC*** Negative Meaning Experience of cancer is misunderstood “Never-ending” leads to hopelessness On-going symptoms Negative Emotions Changes in Cognitive Ability Loss of Control Positive Meaning Positive Re-Appraisal Altruism / Giving Back Cancer as a “gift” Motivated to healthy behaviors Mindfulness Urgency of Life ***Gendered Role in Conflict*** Expectations of Self Shift from Caregiver to Care Receiver Becoming Self Interested Fear of becoming a burden to others Expectations of Others HCP / Patient Compliance ***Silenced Breast Cancer Survivor*** Expectations of Self Individualistic “Me Centered” Guilt related to becoming a burden to others	***Emotion Work +*** Emotion Management (for the sake of self) Experience of cancer is misunderstood Loneliness / Fear / Anxiety Loss of Control Mindfulness (living in the moment) Expectations of Self Markedness (Stigma) Emotion Labor (Work – for the sake of others) Surface Acting Deep Acting (internalized / embodied) ***Grief Work (Stages) +*** 1. Denial, Numbness, Shock, Disbelief 2. Anger, Disequilibrium, Developing Awareness 3. Bargaining, Restitution 4. Depression, Disorganization / Despair, Resolution of Loss 5. Acceptance, Reorganization, Recovery 6. Fight & Hope ***Identity Work*** Role Choice Behavior Perceptual Control

Level 1	Level 2	Level 3
Preliminary Categories	Transformed Categories	Delimited Theory
Internal / External Factors	**Identity Roles**	**Survivor Work =**
effected by) Altruistic Pursuit Cancer is a Gift Concealing Fears/Symptoms, Feelings Coping Mechanisms Distraction Fear of Recurrence Giving Back Loss of Control Loss of Self Pressure to act normal or like a hero Seeing Life as Precious Self-Interestedness Socialized Silence Thoughts Uncertainty ***Social Factor (effects, or is effected by)*** Fear of Recurrence Healthcare System Loss of Friendships Patient Role Sexual Function Sick Role Social Support Socialized Silence Stigma & Disclosure Support Groups Thoughts ***Spiritual Factor (effects, or is effected by)*** Altruistic Pursuit Cancer is a Gift Positive Reappraisal Resource Seeing Life as Precious Uncertainty	Socialized Silence Expectations of Others Pressure to act like a “hero” or normal Concealing fears, symptoms, true feelings ***Challenged Womanhood*** Body Image Markedness Stigma & Disclosure Sexual Function ***Person in Need of Support*** Emotional Support Other WSBC / empathy Support Groups Instrumental Support End of Treatment Sense of loss Shift from HCP to self-monitoring Fear of recurrence	

Internal / external factors.

Themes related to the nature of survival for breast cancer survivors began to emerge naturally beginning from the initial research and literature review. The understanding of breast cancer survival has evolved within the major government, heath care, and breast cancer organizations due to factors that have extended survival past the earlier definition of survival. Therefore, the cultural and historical meanings of cancer, in this case breast cancer, provided a background to better understanding breast cancer within American society.

In order to better understand the idea of the hidden or secret meaning of breast cancer survival across cultures, which I viewed as the thought life or cognitive processing, these hidden thoughts, needed to be exposed. These were hidden because they were thoughts that were often not spoken directly but were alluded to in the spoken word and were revealed interpretively in the research. By focusing on the concept of thought life, aka cognitive processing, through research done for a presentation at Trinity College, Dublin (2010) titled "Cognitive Processing Issues of Women Survivors of Breast Cancer Across Cultures," my understanding of the impact of psychosocial factors upon this thought life matured, and six discrete factors emerged from the data. The six factors that emerged included emotional, psychological, social, spiritual, physical and financial areas. Within these factors I successfully captured the nuances that were missed with a single category of psychosocial. However, I initially failed to understand the importance of body image and sexuality, and placed body image, sexuality, sexual function and desire within these categories rather than as a separate and distinct category titled body image and sexuality as previously discussed in the Literature Review. Dublin's paper also demonstrated that the meanings related to the six factors, including body image and sexuality, differ across the cultures studied: African American; Asian American; Caucasian and Latina women. Additionally, acculturation and assimilation impact the strength and direction of these meanings.

The findings were coded against the discovered Internal / External Factors, defined as follows:

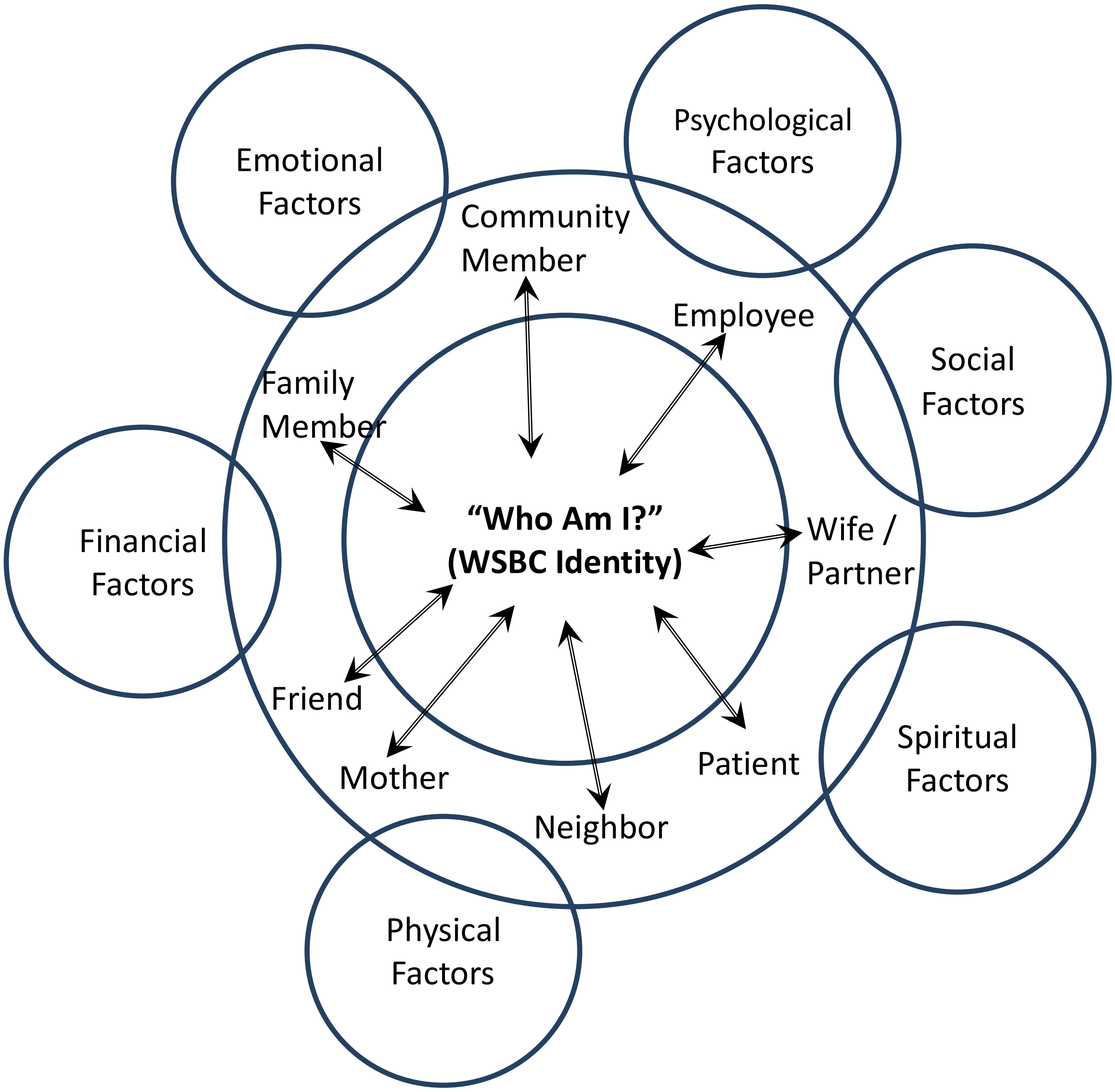
1. Emotional: A factor related to a conscious mental reaction (as anger or fear) subjectively experienced as strong feeling usually directed toward a specific object and typically accompanied by physiological and behavioral changes in the body.
2. Financial: A factor related to the management of money, banking, investments, and credit.
3. Physical: A factor of or relating to the body.
4. Psychological: Of, pertaining to, dealing with, or affecting the mind, especially as a function of awareness, feeling, or motivation.
5. Social: Social interactions are the acts, actions, or practices of two or more people mutually oriented towards each other's selves, that is, any behavior that tries to affect or take account of each other's subjective experiences or intentions.
6. Spiritual: Of or pertaining to the spirit or soul, as distinguished from the physical nature.

The edited findings of the breast cancer survivor Internal / External Factors have been summarized in Appendix C, Synthesized Findings 1: External / Internal Factors. By expanding the coding to include the six factors, it became clear that these factors were pressure points that women experienced from outside sources, such as spouses and other family members, employers, friends and society, as well as internally … from their own thoughts. For instance, an external factor from the outside in could be a friend trivializing the impact of chemotherapy on forgetfulness by stating “I forget things all the time.” The breast cancer survivor would feel compelled to manage their emotions and produce a socially acceptable response such as laughter rather than state, “This is different. I have breast cancer.” This is because they know that their friend is trying to be helpful. An example of an internal factor might be the fear and stress a breast cancer survivor experiences in anticipation of a recurring checkup or mammogram.

The selected articles infer that the women's response to the inner/outer pressures of the six factors impacted the roles that breast cancer survivors played in the course of their survivorship. These roles served to define, for the survivor, who they perceived themselves to be, or to have become in various situations … their Identities. I recoded again to include newly defined roles and identities. The shift in focus changed the major themes to the identities and roles and redefined the psycho-social (psychological, social, financial, etc.) as the factors influencing the roles survivors play as they struggled with their conflicts with the expectations of others as they negotiated the stages of breast cancer and survivorship.

There are eight identities listed in this paper, two of which are generally considered gendered identities. They are: wife/partner, patient, neighbor, mother, friend, family member and, community member. However, though it was obvious that gender has an impact on meaning and lived experience, the roles and identities were initially viewed as a given, rather than positing their having the most salient impact on the breast cancer experience. For instance, the effect of breast cancer on body image and the resultant concerns related to issues such as sexual relationships, performance and fertility became a significant concern, especially to those younger, pre-menopausal survivors. In addition, the role of caregiver, assigned to the wife/partner and mother, became a major issue with regards to role conflict and disruption. The Venn diagram (Figure 4) illustrates the relationships and interactions between the internal/external factors upon the roles and identities and vice versa.

Figure 4: Venn Diagram, Relationships between Identity, Role and Internal/External Factors



The issue of pressure for women to return to their roles more quickly than many breast cancer survivors felt able to is certainly influenced by popular culture's marketing of breast cancer as a pink ribbon moment rather than a serious disease with lifelong ramifications. The stigma of breast cancer still exists, for example, the belief that the survivor is guilty of their own disease due to a failure to follow healthy practices. That said, the meaning of breast cancer across cultures within American society adds another layer of depth and understanding for health care professionals due to cultural meanings and practices.

Role Domains

Subsequent to the coding against Internal / External Factors, the findings were re-coded against identity roles that emerged from the data. The discovered identity roles are defined as follows:

1. Friend: A person whom one knows, likes, and trusts. An acquaintance.
2. Mother: A female parent
3. Wife / Partner: A female partner in a marriage or otherwise committed relationship.
4. Patient: A person under health care. The person may be waiting for this care or may be receiving it or may have already received it.
5. Neighbor: One living or located near another.
6. Community Member: Member of a community defined as an interacting population of various kinds of individuals in a common location.
7. Employee: One employed by another usually for wages or salary.
8. Family Member: A member of a group of individuals, possibly living under one roof and usually with one leader or two involved in co-leadership.

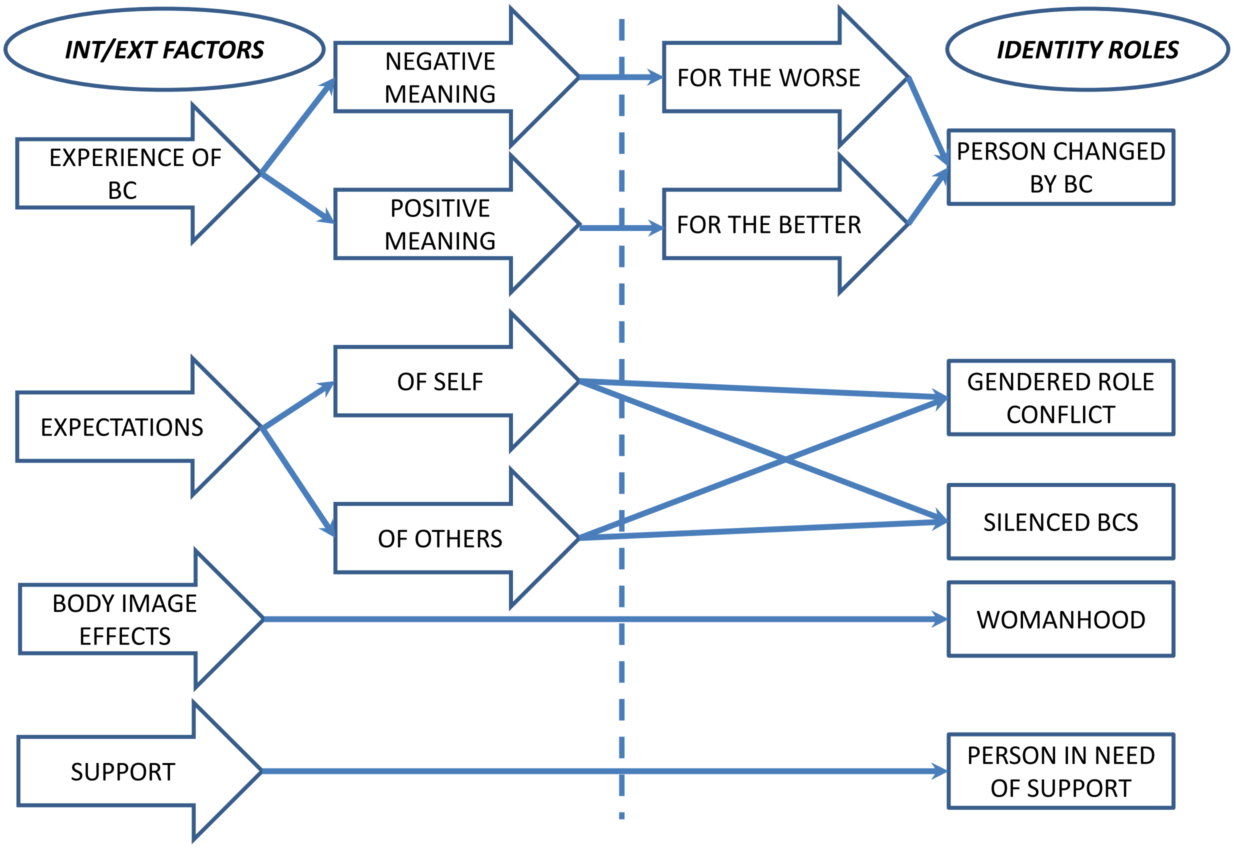
The findings against these breast cancer survivor identity roles have been summarized in Appendix B, Synthesized Findings 2: Developed Roles.

The interrelationships between the Internal and External Factors, and the Identity Roles were further explored, resulting in a set of five (5) transformed categories that included:

1. A Person Changed by Breast Cancer
2. A Gendered Role in Conflict
3. A Silenced Breast Cancer Survivor
4. Challenged Womanhood
5. A Person in Need of Support

These relationships are visually displayed in **Figure 5**.

Figure 5: How Internal/External Factors Impact Identity Roles



A person changed by breast cancer.

The experience of breast cancer, as evidenced across all articles, identified a dominant theme for women survivors of breast cancer as being forever changed. Phrases like: “Life will never be the same” and “cancer is life changing” were repeated in every article reviewed. However the experience of cancer had both a positive and negative meaning for the survivor. This multiplicity of meanings demonstrated how breast cancer affected them for the better, and/or for the worse, and formed their identity as a person forever changed by breast cancer.

Breast cancer survivors reported that the cancer experience forced them to reappraise their life, which for many, led to positive changes in lifestyle, such as stress reduction and health behaviors. They felt urgency to follow their dreams, change careers, go back to school, travel, etc. Many became volunteers and generally adopted a more altruistic lifestyle.

The breast cancer survivors in the articles under examination all experienced a persistent fear of cancer recurrence. This fear was experienced in all phases of the survival experience and could be triggered by seemingly the most benign conversation, visual or sensory experience, or other factor. Those around them assumed that the experience of cancer was over when treatment was over. However, the end of treatment did not signal the end of the psychological and physical issues of having cancer and cancer treatment, such as fatigue, weight gain, loss of hair and libido, and changes in cognitive ability. In fact, the most difficult time for many breast cancer survivors began after treatment, when consistent contact and monitoring with health care providers ended, and when family, friends and employers expected the survivor to return to life as usual. Therefore, the shift from sick to well for breast cancer survivors was not clear-cut. Breast cancer survivors, as noted previously, were forever marked both internally and externally as one who experienced cancer and who continues to experience the impact of cancer.

Gendered role conflict/silenced breast cancer survivors.

In this study, the idea of woman as a traditional gender role and traditional gender identity was adopted since the outcomes of each study produced the parameters for such a designation. There was no evidence provided that the women in these studies did not have anything but a traditional gender role and traditional gender identity. This had significant impact on the women's real and perceived ability to perform what is generally considered part of the role of being a woman, mother, daughter, wife/partner, as well as a friend.

Across the board, the women in this study had difficulty negotiating the shift from caregiver … one who gives of herself to others, to one who is taken care of and one who allows others to care for her and/or focuses on her care. Many of these women were previously caregivers of family members and kinship groups consisting of relatives and adopted family. This struggle included the fear and guilt of becoming a burden to others. These women, especially Asian American and Latina women, felt pressure and a disproportionate need to return to their traditional roles as mothers, wives, friends, and caregivers. In addition, these women reported pressure from others to adopt the popular culture model of a woman survivor of breast cancer as a strong and silent hero. These survivors reported that family, friends, employers and colleagues, even health care providers voiced these expectations.

The breast cancer survivors stated that they put pressure on themselves to be silent with friends, relatives, employees and especially neighbors based on perceived and real negative consequences that, when they did express themselves, tended to result in stress and discomfort on the part of survivor. Women changed jobs rather than let employers know that they had cancer. Some women expressed that they minimized the impact of treatment to their doctors because they thought they would receive better care if they did not complain and were perceived as an easy patient. A component of the women reported that troubled relationships were further weakened by the illness. Women expressed that they did not remember cancer being spoken about when they were children and thus, sensed that it was something to worry about. All women felt some sense of shame about getting cancer. With the exception of Caucasian women, women represented in the other cultures, viewed cancer as a taboo.

For example, the taboos within the African American community against discussing cancer sometimes inhibited diagnosis, treatment and support for cancer. This is confirmed by Karen Eubanks Jackson, an African American breast cancer survivor and founder and CEO of The Sisters Network, Inc. Ms. Eubanks Jackson wanted this foundation of African American women breast cancer survivors to "break through the silence and shame of breast cancer." She further stated that cultural taboos about speaking of and talking about breast cancer "immobilizes African American women, restricts their ability to receive support services interferes with early detection, and ultimately affects their survival rates" (Sisters Network, 2012, p. 3).

The studies that included Latina and Asian American survivors had strong indications and stated content that the women were situated in traditional gendered roles. Though women that were more acculturated shifted more or less to the cultural meanings of the Caucasian women, the stated, summarized and implied responses of the women confirmed the assessment of traditional gendered roles. African American women identified in the studies, included indicators of both traditionally gendered relationships and kinship groups that consisted of other women who provided care and support, another culturally common dynamic for this population.

Challenged womanhood

Breast cancer survivors experienced negative feelings related to the changes in their body that impacted their body image, which may further impact their sexual functioning, ranging from diminished to non-existent function. The breast cancer survivors felt that their body betrayed them and, in a sense, they faced both disembodiment and embodiment. This betrayal both disconnected them from control of their bodies and changed their connection from a healthy body to a sick body and began at the pronouncement of having cancer but continued through the treatment for cancer up to and including, the rest of their lives. Some African American and Latina women had concerns about dating, related to how their altered body might impact present and future relationships. Male support was an important and desired aspect of surviving breast cancer. Even so, some African American survivors seemed to be especially effective in separating the effect of their changed body image from their ego identity, and stated in the selected findings that "they were not their breasts" and that their breasts did not necessarily fit their definition of an "attractive black woman".

A unifying theme throughout the selected studies was that treatment for cancer, whether invasive or not, enters and marks the body. The breast cancer survivor becomes marked and visibly different from everyone else. Some of the physical impact of the changed body may not be felt or seen immediately but these changes are felt and/or seen as the survivor ages. This poses another issue of the impact of breast cancer treatment compounded by aging.

In my analysis, I found that the women reported that others frequently trivialized these body image effects. Breast cancer survivors were seen as being lucky to be alive. For these women the issues encountered which relate to body image and sexual functioning were considered minor in relation to death or life. Regardless, the effect of a changed body image continued to inform and impact the thought life of survivor.

A person in need of support.

A key finding suggested that a woman survivor of breast cancer is a person in need of support, particularly support from health care providers within the continuum and quality of care. Many women reported feeling a sense of loss and abandonment at the end of treatment. They were afraid of having to monitor themselves and expressed concern that they would miss signs of recurrence. Asian American, Latina and African American breast cancer survivors experienced barriers and/or discriminatory treatment in accessing care from the start. As previously stated, African American survivors expressed an undercurrent of distrust of the healthcare system, related to fears of racism and events that reached back through the generations.

Another support issue had to do with employment. The very women without resources in these studies were the women most vulnerable to job loss due to issues with treatment and illness. This was particularly problematic for African American and Latina breast cancer survivors. Many African Americans and Latinas lack comprehensive health care insurance, if they have any at all. Survivors linked financial stability and insurance status with effective treatment leading to survival and studies indicate that this may be true. African American women tend to be diagnosed later and receive different intervention, while Latinas struggle with lack of insurance and language difficulties that can impact care. A particularly strong issue for Latina breast cancer survivors was the disproportionate impact to employment, with many losing their jobs due to excessive absences or changes in work performance due to treatment and ongoing symptoms. Conversely, many Latina survivors stopped treatment altogether to maintain their positions. This may have been due to the types of jobs and the resulting lower wages that Latinas are able to obtain. In 2007 it was reported that the median weekly wage for Latinas who worked full time in 2007 was $460 as opposed to non-Latinas who earned $615. Another comparison that further illuminates the issues related to race, class and gender is that Latinas earn 55 cents to each dollar that a man earns. Fifty-three percent of Latinas live in low-income households while 46.6 % are headed by Latinas with children in poverty. Of course, this does not reflect Latinas whose income is not reported or the undocumented Latinas who work in the United States (American Progress Action Fund, 2008).

Caucasian women, due perhaps to the dynamics of white privilege, were least impacted by the financial ramifications of breast cancer, such as job loss and treatment costs, and were able to stop working if they were employed before the diagnosis. This was in contrast to Latina and African American women who struggled through working, even changing jobs if necessary, to protect themselves from disclosing a breast cancer diagnosis. Additionally, this ethnic group reported instances of having to stop treatment due to employment and related financial issues.

Family and friends can be a good source of support but also can be a source of stress. Asian Americans expressed the importance of support from family members for emotional well-being, treatment adherence and overall recovery. African American women expanded the definition of family to include friends who acted as caregivers and provided themselves and their homes as a place for healing and recuperation. However, they similarly reported that the pressure to perform and act as if all was well was draining.

Some Latinas reported that spouses and partners abandoned them after diagnosis. The studies suggested that these men felt that the woman’s damaged body, particularly what was considered a sexual body part, reflected poorly on their machismo. Therefore, this was a particular concern for Latinas whose self-acceptance depended on their partner or spouse’s acceptance. Additional lack of support was demonstrated with Latinas who mentioned that relatives told them that they would die from the illness. One African American woman mentioned that she was unaware that there were other women in her family that had breast cancer until she was diagnosed with cancer herself. Some African American women expressed an increased sense of purpose and will to live for themselves and their family.

Support groups, particularly culturally specific support groups, helped women manage their fears and concerns. Many breast cancer survivors found support from their spirituality; whether derived from a formalized or informal setting. This was particularly true for African American and Latina breast cancer survivors. African American survivors especially, spoke of the strength gained from their relationship with God and the desire that to be treated by a health care provider who believed in God. The African American breast cancer survivor also realized support within the larger community of African Americans, which included their neighborhoods, and was expanded to other church and social networks in which they participated. Less acculturated Asian American breast cancer survivors emphasized the importance of religious beliefs in handling illness.

Survivor Work - Survivor Identity

The process of theory development continued and, through constant targeted comparison of the findings, a final synthesized interpretation of the integration of emotion work, grief work and identity work emerged as a theoretical framework for survivor work, leading to a new survivor identity (Level 3). It became apparent that the woman survivor of breast cancer was experiencing a combination of effects that impacted her from both within and without and required a significant and ongoing process of survivor work, which includes doing emotion work, grief work and identity work in order to establish this renewed identity of survivor. Once again, the data was re-coded against these newly emerged themes. The updated coding structures can be found in Appendix B: Figures 8, 9 & 10).

This resulted in the identification and categorization of related sub-themes that sought to provide a unified interpretation of the relationships between internal & external factors that formed the experience of the breast cancer survivor and the impact of those experiences on the roles played by the survivor, and therefore their identities.

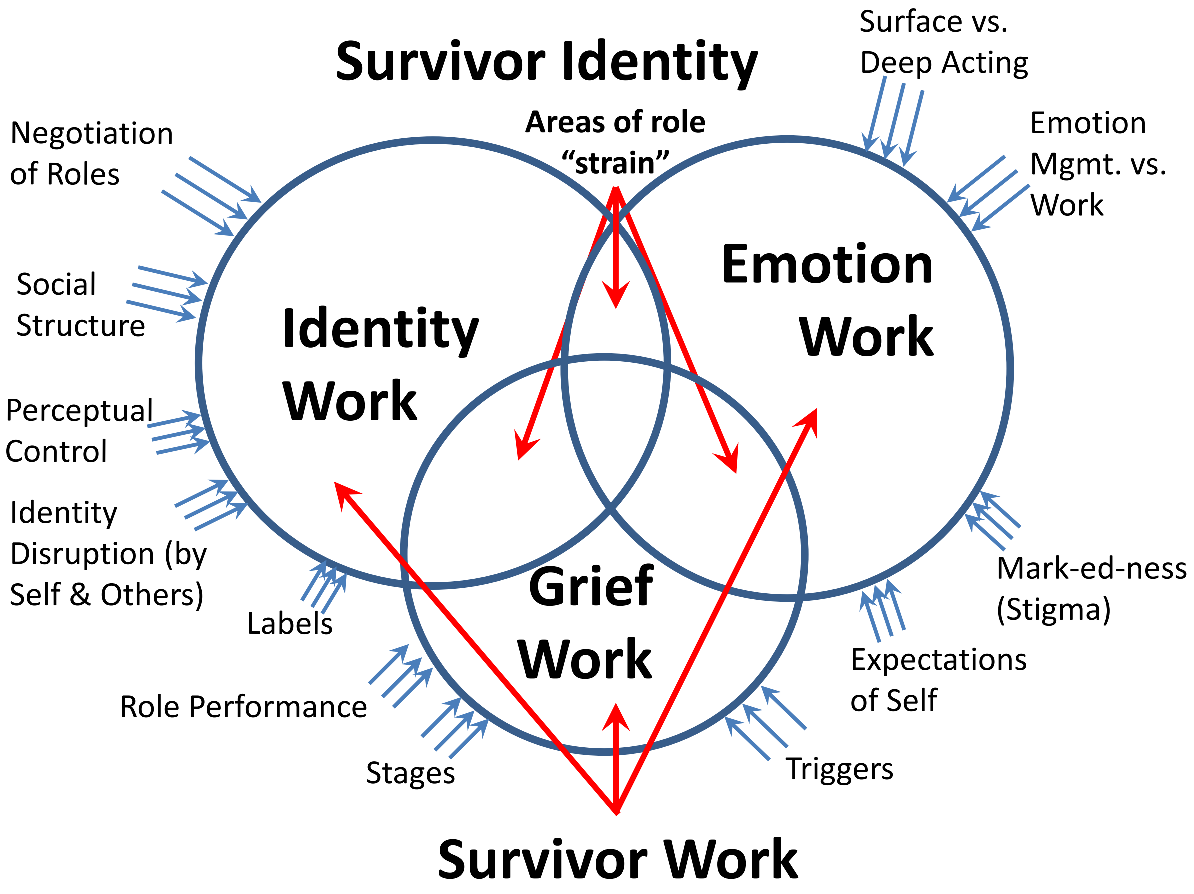
The indicated identity themes are:

1. Emotion Work
    a. Emotion Management
    b. Emotion Labor (Unpaid Work)
2. Grief Work
3. Identity Work
    a. Role Choice Behavior
    b. Perceptual Control

These relationships are visually displayed in (Figure 6) and are discussed below. As the Venn diagram illustrates, the work of emotion, grief and identity are not always independent processes but may be interrelated and subject to the dynamic experience of breast cancer survival from diagnosis until death.

The dynamic of interrelatedness is important and is best illustrated using a fictional example. If we were to assume that a breast cancer survivor, named Mary, had just scheduled her upcoming follow-up visit with her oncologist, she may be faced with the following. In preparation for the visit, Mary may review the history of symptoms she has experienced over the last several months. Possibly she has experienced severe fatigue and pain in her back or hips. It may just be due to pressures and stress at work, and a poor mattress, but Mary ruminates over these symptoms, recognizing them as a possible sign of recurrence, manifested as bone cancer. Of course, Mary keeps these fears to herself, regulating her emotions in front of others, since their perception is that breast cancer is a past event, and she should be beyond it. As Mary drives to her oncologist she struggles with what she should reveal to her doctor, since she does not want to damage the relationship of trust that has developed between them. Of course this trust is based on two roles … the doctor's role as healer, and Mary's role as patient who has become survivor. During the visit, the oncologist reviews the results of recently completed tests and states that there is something that showed in her last mammography that will require additional tests. He does not believe that it is anything to worry about, but he just wants to be cautious. This releases a flood of fears and negative emotions, catapulting Mary back into stages of grieving for her loss …a loss that she believed she had already resolved. She is now no longer a survivor, but once again, a patient. Once again, she must regulate these emotions, both for her own sake, and for the sake of others. She fears that her family will become overly concerned, or possibly draw away from her, not wanting to deal with their own fears again. As can be seen from this illustration, the survivor work, which includes the dynamics of emotion work, grief work and identity work all come into play during this one event. It should be noted that these responses will vary depending upon the age of the survivor and ethnicity, since the cultural dynamics impact all areas of identity.

Figure 6: Survivor Identity



The initial shift from pre-breast cancer identity to post-breast cancer identity can be likened to an earthquake. Once the earthquake hits, everything is different and nothing will ever be the same. A woman survivor of breast cancer is identified as a survivor as early as the moment of diagnosis (National Cancer Institute, n.d.). For some, the identity of woman survivor of breast cancer was negotiated by embracing the popular symbols, such as the pink ribbon, while others prefered to distance themselves from the identity and symbols associated with breast cancer (Kooken, 2007; Sulik, 2007; Kaiser, 2008). Goffman referred to this as role distance (Marx, 1984). More challenging, an imposed identity of breast cancer survivor means being forced into a new social world, learning the new role(s) and tasks associated with them and deciding how they will and will not meet others' expectations In other words they begin role-making (Mathieson & Henderikus, 1995; Kaiser, 2008) and new identity formation.

Three domains were identified in the final interpretation of the synthesized findings. These domains are emotion work, grief work and identity work, all of which require the work and management of the breast cancer survivor and other persons' related meanings. This process, along with the aforementioned social, physical, financial, spiritual, psychological, and emotional factors, impacts how breast cancer survivors choose to navigate and experience the meaning of breast cancer survival and form a new identity. Once diagnosed, all of these factors and domains can, again, be viewed from the inside out and from the outside in. Their thoughts and actions may impact others, and the thoughts and actions of others may impact them. Breast cancer survivors immediately are faced with their mortality and wonder how their families, especially their children, will fare without them. They may minimize or remain silent about these concerns to protect themselves and their children from the fear of such a loss. In addition, they seek to protect themselves from friends and family members who deny survivors any negative thoughts, and/or to protect those friends and family members themselves from negative feelings. These newly diagnosed breast cancer survivors are dealing with a new world and a new role and an identity that defines them as sick (Goffman, 1963). This threatens to compromise most every other area of their life. Many women had problems negotiating new roles that posed a conflict with societally defined gender roles and the expectations that those other roles carry. This complicated the emerging negotiation of a new identity. A summary of this edited data, along with the synthesized findings can be found in Appendix C: Synthesis of Edited Findings..

A frequency manifest effect size table was developed to validate the salience of the emergent themes and their associated sub-themes. This data is not indented to represent the intensity of the themes as they relate to the woman survivor of breast cancer, but only the prominence within the reviewed data. (Table 9: Frequency Manifest Effect Size).

The data also confirms the interrelatedness of the themes, showing that codes, and their related findings, occur in multiple areas of the work of establishing a survivor identity. These findings are to be seen in the context of emotion, grief and identity work. The same recurring findings may result in emotion work as well as identity work, or grief work and emotion work … or all three. As such, the findings, and the resultant interpretations are discussed in the following sections

Table 9: Frequency Manifest Effect Size

Major Category	Sub Category	Code	Frequency		Major Category	Sub Category	Code	Frequency	
All			399						
Emotion Work			303		**Identity Work**			251	
	Emotion Management	Total	105	35%		**Role Choice Behavior**	Total	70	
		self interestedness	41	39%			role conflict	23	33%
		fear and guilt related to becoming a burden to others	22	21%			expectations of self	16	23%
		ongoing symptoms	21	20%			increased role strain	16	23%
		fear of recurrence	18	17%			shift from care giver to care receiver	15	21%
		expectations of self	16	15%			expectations of others	15	21%
		shift from care giver to care receiver	15	14%			support groups	14	20%
		uncertainty	9	9%			gendered role conflict	13	19%
		cancer is a gift	3	3%			acculturation	7	10%
		mindfulness	2	2%			pressure to be normal	3	4%
	Emotion Labor (unpaid work)	Total	94	31%			pressure to be a hero	3	4%
		role conflict	23	24%		**Identity Disruption**	Total	128	
		HCP sensitivity / communication	22	23%			body image	62	48%
		Patient compliance	19	20%			stigma & disclosure	33	16%
		increased role strain	16	17%			ongoing symptoms	21	16%
		expectations of others	15	16%			life changing nature of BC	14	11%
		gendered role conflict	13	14%			loss of self	14	11%
		concealing true feelings	11	12%			sexual function	13	10%
		language / communication	10	11%			loss of control	10	8%
		concealing symptoms	6	6%			pressure to be a hero	3	2%
		concealing fears	6	6%			pressure to be normal	3	2%
		pressure to be a hero	3	3%					
		pressure to be normal	3	3%					
Grief Work			193						
	Stage1: Denial, Numbness, Protest, Shock/Disbeli	Total	57	30%					
		stigma & disclosure	33	58%					
		acute stage	22	39%					
		socialized silence	9	16%					
	Stage 2: Anger, Disequilibrium	Total	69	36%					
		emotional factor+negative meaning	52	75%					
		end of treatment	24	35%					
	Stage 3: Bargaining, Restitution	Total	31	16%					
		shift from care giver to care receiver	15	48%					
		WSBC's womanhood	13	42%					
		feminine beauty	3	10%					
		pressure to be normal	3	10%					
		pressure to be a hero	3	10%					
	Stage 4: Depression, Disorganization, Despair	Total	113	59%					
		body image	62	55%					
		role conflict	23	20%					
		increased role strain	16	14%					
		sexual function	13	12%					
		loss of control	10	9%					
		isolation	9	8%					
		loss of friendships	5	4%					
	Stage 5: Acceptance, Reorganization, Recovery	Total	50	26%					
		positive reappraisal	34	68%					
		healthy behavior	24	48%					
		taking control	23	46%					
		urgency of life / life as precious	15	30%					
		altruistic pursuit / giving back	12	24%					

Emotion work.

Emotion Management is the work of controlling emotions in order to present oneself in culturally or ideologically acceptable ways for one's own benefit (Hochschild, 1983). Emotion Work (Labor), controlling ones feelings to reflect others expectations, is also work. People work on their feelings in order to provide the proper response to a given situation and adhere to the situationally-based, socially determined feeling rules. Breast cancer survivors work on both of these. As previously stated, the initial disclosure of being diagnosed with breast cancer comes at the treatment decision-making time, a critical time for the survivor that may require a significant amount of effort and energy in responding to perceived expectations.

In her article, "Sisyphus and Other Everyday Heroes" (2003) Hester Hill Scnipper, an oncology social worker and a cancer survivor, speaks about her work with women in various stages of breast cancer. She notes how, "We all understand the truth of our shared uncertainty as we learn together how to live out loud" (p. 91). Living 'out loud' may indeed mitigate some of the fears and issues facing the breast cancer survivor. This was a concept that I sought to examine. I wondered if survivors controlled their fears? If so, how did they manage them? Or did they control what they said? Francis (1997) explores the impact of bereavement and divorce support groups who "accomplish emotional and cognitive change in individuals…" (p. 1). The focus is "on the process by which others can shape, work, and manage our emotions" (p. 1), in the context of this study, the modification and management of the survivor's emotions by others. However, I questioned if there were truly cognitive and emotional changes, or rather an improved management of the spoken word? Based on the findings, I believe that the articulation of negative thoughts and feelings are silenced in order to either portray to others one's healing of the grief and loss, rather than a genuine working through, or to avoid the perception of others, that the survivor is ungrateful for being alive. In reality, this suppression of the negative thoughts and feelings mitigates other's anxiety and not the survivor's.

In addition, it should be noted that breast cancer survivors in this analysis had to deal with triggers and issues throughout their lives that required other types of work, along with emotion work. Fear of recurrence was strong and could be triggered by: any physical symptom of an unknown origin; follow-up visits to a health care practitioner, hearing something on TV or from others about breast cancer; someone being diagnosed with breast cancer; annual exams; heightened tension about follow-up calls from physicians; time waiting for test results; responses to physicians' questions during office visits. Besides fears of recurrence, they feared death, pain, and suffering (often identified as a larger fear than dying.) They struggled with their identity after treatment due to lack of preparation for ongoing symptoms, especially fatigue. Due to the concern of recurrence, breast cancer survivors resisted being labeled as cured, and were uncomfortable with the term cancer survivor. One woman used the term patient suggesting that she had not made any transition. These fears were exacerbated when treatment ended and they were unsure of which ongoing symptoms required a trip to the health care provider. The ongoing symptoms caused stress and anxiety, loneliness and helplessness. This included managing their emotions due to others' sense that the breast cancer was over. This sense of others that the breast cancer was over was also part of the popular discourse. Breast cancer survivors reported feeling pressured by others to act like a hero.

Role conflict.

The findings revealed many examples of role conflict and increased role strain. The pressure of others' expectations for breast cancer survivors to return to normal challenged the survivor to return to roles and tasks that they were not able to accomplish due to the physical, emotional and psychological stress of living with and possibly dying of a life threatening illness. Women also struggled with retaining their womanhood both in the physical body and in the emotional sense due to the fact that they are typically socialized to care for and give to others … to be caregivers. Survivors felt pressure from others and from within to function in the way they perceived they should function to maintain their status as a good wife/partner; mother; family member; friend and neighbor. Many women reported pressure from others to be strong, to act like a hero, to go back to their former level of functioning. This was especially true for Latinas, They felt pressured to look better than they felt in social situations, at work, with friends and family. This occurred concurrently with a new sense of self-confidence, empowerment and/or individual identity and often conflicted with others' expectations, which resulted in feelings of selfishness and guilt.

The gendered role conflict seemed to be the dominant issue that breast cancer survivors faced. This is consistent with the contemporary symbolic interactionist view of society as encompassing highly differentiated and yet organized systems of interactions and relationships that cross all lines of distinction based upon age, gender, ethnicity, religion, etc. Accordingly, the identity of woman is inseparable from all other roles played by the survivor.

Gender and emotion work.

In the chapter Gender and Emotion in "The Handbook of the Sociology of Emotions" (Shields, Garner, DiLeone & Hadley, 2007) emotion is posited as a gendered stereotype for women, and is viewed "as good (e.g., warm: nurturing) and as bad (e.g. too emotional). Thus, gender as a background identity carries with it consensual status beliefs regarding emotion" (p. 66).

Breast cancer survivors struggled with their conceptions of their roles as women and their new strength and desire to focus on themselves. The gendered role reversal related to being taken care of by others, especially men, created issues for the men, as well as the survivors. Most survivors continued to care for others while carefully minimizing the care they took from others, especially men, as part of their self-imposed expectations. They chastened and/or silenced themselves when with other survivors who they thought were selfish and who did not demonstrate a strong fighting spirit. Some Asian American breast cancer survivors did not seek help from family for daily chores during treatment. African American, Asian American and Latina breast cancer survivors were worried about the impact of their illness on their families. An Asian American woman expressed concern about dating as a breast cancer survivor.

Family members struggled with assuming their new roles as caregivers. Conversely the survivors struggled with their role reversal as care receivers and the resulting role strain as they sought to manage the expectations of others. Breast cancer survivors used two interrelated processes to manage this: justifying their needs to themselves and others; and being self-reliant to avoid being burdensome to others. Survivors felt it important to give back to others by continuing their hospitality to family and friends and for some; to carry out God's will for their lives. African American breast cancer survivors continued their tasks of caring for others in spite of the fatigue it caused, and saw it as a positive way to deal with their illness. A strong theme of popular culture's salience of gender, especially compliance to others' needs and desires with no thought of their own needs and desires emerged. In spite of this, the survivors' personal perspectives and priorities allowed for negotiating space for themselves and finding new meaning in their lives. While empowering, it also caused tension and identity ambivalence.

Women felt pressure to conform their behavior to societal gendered roles, norms and meanings causing pressure to behave in certain ways requiring habitually gendered performances (Butler, 1990). The reversal of gendered norms relating to men caring for the breast cancer survivor created problems for couples since the men did not know the skills and amount of energy that caring for others required. The gendered expectations of sacrifice, empathy, and emotional sensitivity conflicted with the self-interestedness necessary to cope with breast cancer. The breast cancer survivor's inability to override gender norms resulted in a failure to meet others' expectations.

When focusing on doing emotion as doing gender it may signify surface acting, a performance that is meant to manipulate others' impressions without internalizing them (Shields, Garner, DiLeone & Hadley, 2007, p.66) or deep acting, a high level of embodiment and assimilation of what one is thinking and feeling to how they perceive others want them to react. People, who engage in deep acting often, and over long periods of time, become "estranged from their feelings. They develop a false and alienated sense of self" (Boynes, 2007, p.271). This may be one of the reasons that some breast cancer survivors report feeling lonely and isolated. The inability to present the genuine self for the sake of others and self does distance one from authentic and meaningful relationships leaving them isolated from others and themselves.

The findings showed that families, at times, caused strain for the breast cancer survivor. The realization that others were not aware of the ongoing issues of breast cancer caused women concern about disclosing fears or telling the truth about their illness, symptoms, triggers and memories such as an upcoming mammogram or an anniversary related to breast cancer. This was especially true for Asian American and Latina breast cancer survivors who did not want to burden their families and/or deal with their reactions. This led to a sense of loneliness. Survivors silenced themselves, masked their feelings and did not fully share aspects of their experience or fully reveal themselves. Distress was compounded when women felt misunderstood or were accused of feigning or exaggerating their symptom experiences. Breast cancer survivors withheld symptom complaints from their health care providers so as not to negatively influence or risk the loss of their relationship.

The isolation and loneliness provides a rationale for support groups as a means of presenting self-authentic roles with others who may feel the same way. However, not all support groups have the goal of achieving self-authenticity. As demonstrated in both Thoits (1996) and Francis (1997) emotions are managed in support groups through approval and disapproval for meeting or not meeting the emotion norms of the group. This approval/disapproval comes from group members as well as group facilitators. Support groups that are composed of same culture participants can work as a stronger means of support, or not, depending on the level of acculturation and the skill of the facilitator.

Some young and/or less acculturated women who had specific cultural qualities attached to womanhood, saw breast cancer surgery and reconstruction, or any surgery, as a threat to their image as a woman, their sexuality and to their gender identity based on their ability to catch or please a man. This requires a great deal of emotion work. Though surgery might save and/or lengthen their life, they may refuse treatment via surgery to comply with cultural meanings. Other women fought against the notion that reconstructive surgery makes a woman a woman by refusing reconstruction and publicizing their scars in order to politicize the physical effects of breast cancer. These decisions regarding surgery and reconstruction are invariably tied to emotion work in that they reflect the survivor’s negotiation of their gendered identity, thereby promoting the personal as well as the political.

Other popular movements reframe the meaning of being a woman survivor of breast cancer through popular symbols, which, as stated previously, some survivors distance themselves from. This movement seeks to elevate the status of breast cancer survivors by framing them as strong and pink. Barbara Ehrenreich (2001) views this as infantilizing breast cancer survivors, though she acknowledges the financial contribution to research it has produced. Most of the women sensed the need to think about, care about and focus on themselves. The process and work of experiencing something as serious as breast cancer created a sense of strength and urgency of life for the survivors. It led to a need to become more self-focused, a personal quality that could be considered contrary to the norm for a feminine role. The survivors saw this as a positive dynamic of their survival, while concurrently being faced with the strain it caused on relationships with others in their lives. The breast cancer survivors talked about life changes such as living in the moment, increased or new spirituality and pursuing long time dreams. Some survivors felt accepted and loved by their spouses/partners in spite of their physical changes while others reported that these changes created difficulties. As noted previously, Latinas were particularly affected since their husbands/partners associated a loss of machismo with the breast cancer survivor’s changed body. Some Latina breast cancer survivors indicated that there were intimacy and relationship issues which resulted in their husbands ignoring or leaving them due to this issue.

Overall African American, Asian American and Latina breast cancer survivors found many issues with health care provider care. They all experienced barriers and/or discriminatory treatment in accessing care, lack of doctor sensitivity in listening to their concerns or in relaying diagnosis, which led to worries about trust and disclosure of information. Asian Americans and Latinas pointed to language barriers, education level and dress as impacting the health care provider’s assessment of them. More acculturated Asian Americans felt knowledge about the illness and medication positively impacted the health care provider’s impression of them. Therefore, they felt more control over their illness and thereby were able to navigate the barriers that impacted less acculturated breast cancer survivors. Institutional racism had particular meanings for African Americans. The majority of the African American survivors described negative relationships such as doctors discounting their concerns, insensitivity, and that they believed the doctors really did not care about them. They reported that they were treated disrespectfully for asking questions. Survivors told of health care providers who exhibited behaviors that contributed to distrust. These encounters included being talked about as if the patient were not present and feeling that the physician did not want to touch her because she was African American. These kinds of interactions led these women to believe that it was safer to be self-reliant and caused some African American women to discontinue treatment. Finally, following a period of acute care, the breast cancer survivors were dismissed by specialists without warning or transition plans; and the survivors felt that the specialists were annoyed with any questions and concerns.

Grief work.

Grief work can be seen as a sub-set of emotion work. In this context, an understanding of grief work as it relates to the breast cancer survivor is important to recognizing the intensity of the emotion work that the survivor is faced with. The experience of breast cancer is one of loss on many levels. The survivor grieves for this loss, both anticipated and realized, in ways that are very similar to the process of grieving someone’s death, or the loss of a career for a wage earner. Chapman & Pepler (1998) describe grief as the "progression of emotional, social, spiritual, physical, cognitive and behavioural changes through which an individual attempts to reorganize and resolve, or adjust to, a loss at his or her own pace" (p. 226). The stages of grieving a death, as defined by Kubler-Ross (1969), can be applied as a loose framework for the process of grief and loss for the breast cancer survivors. There are, however, significant departures from the strict application of the Kubler-Ross model, in that the breast cancer survivor's journey is not a sequential one, nor does it flow from one distinct stage to another. The survivor, due to the on-going nature of the experience, is faced with a cyclical journey, being thrust back to the earlier stages of grieving when recurring medical tests are questionable, physical symptoms lead the survivor to question their health and fear recurrence, or when reports, stories or experiences of others remind them of their tenuous status as survivors. While the breast cancer survivors may not be faced with certain death, she nevertheless is faced with various types of loss, from the existential loss of self, to the physical loss of health and conceptions of feminine beauty, and she must negotiate the emotional trials of this journey of grief.

Stage 1: Denial, numbness, protest, shock & disbelief.

In the first stage of grieving, the breast cancer survivor not only experienced shock and highly negative psychological impact, but it was also marked by concerns regarding both stigma and disclosure. Some of the hesitancy to disclose their illness was rooted in a socialized silence that could be familial and/or cultural/ historical. This was voiced most often by African American, Asian American and/or Latina breast cancer survivors. Other reasons for hesitancy were based on a desire to shield family members from burden, or a concern for disclosing their diagnosis to potential partners. It brought on feelings of fear and shame as to the stigma of being a sick person, and the sense that life had been forever changed.

Stage 2: Anger & disequilibrium.

The second stage of grieving for the breast cancer survivor was filled with feelings of uncertainty, anxiety and abandonment as the survivor transitioned beyond active treatment. Survivors experienced decreased self-worth as they faced a new reality, one framed by physical deformities, impacts to their attractiveness and potential effects to their fertility. This all led to feelings of inadequacy, sadness, embarrassment, frustration and an overall sense of loss.

Stage 3: Bargaining & restitution.

The third stage of grieving for the breast cancer survivor was reflected in the survivor dealing with the stress of changing roles and the pressure, at times, to be someone who they know themselves not to be. They found themselves having to negotiate competing demands and expectations, from within and without, upon their changing roles. While they saw themselves as anything but normal, they were expected to be strong for others and to comply with their needs and desires.

Stage 4: Depression, disorganization & despair.

The fourth stage of Grief Work for the breast cancer survivor is where the real work of grieving took place. Survivors were faced with the prospect of a violated, deformed and dysfunctional body, bodies that were no longer trustworthy. This led to feelings of decreased self-worth, inadequacy, sadness, embarrassment, frustration, vulnerability and loss. The survivor was faced with issues of sexual dysfunction and lowered sexual desire and a concern that interest in sex would never return. The breast cancer survivor expressed feelings of loneliness as they realized that those close to them did not recognize the on-going nature of the breast cancer experience, and wrongly assumed it was over.

Stage 5: Acceptance, reorganization and recovery.

The fifth stage of grieving for the breast cancer survivor is marked by positive aspects of the breast cancer experience. The survivor described a renewed appreciation of the preciousness of life and a sense of empowerment as they moved on to a new state of being. They took charge of their lives and their ongoing treatment and made positive lifestyle changes to prevent cancer from recurring. They developed new attitudes towards cancer and those around them, including for some, valuing spirituality and/or religion. The survivor moved beyond breast cancer, forever a survivor, but also more. A positive transformation had taken place. They saw a heightened appreciation and purpose of life. An altruistic sense of wanting to give back was a common theme, as evidenced by participation in breast cancer advocacy events and support meetings. Again, a common theme was the contribution of spiritual beliefs and a sense of God's intervention in their lives.

Identity work.

Role choice behavior

The contemporary framework of role choice behavior looks at the level of commitment in determining the level of role salience. Commitment is partly interactional, (based on the number of ties in the network), or affective (based on the depth of emotional attachment to the members of that network). Identity salience reflects role choices and the probability that an identity will be called upon in various situations. Identity salience hierarchy is the relative importance of the identities to the person and role choice is choosing to pursue actions of one role rather than another (Burke & Stetes, 2009; Sandstrom, Martin & Fine, 2006).

For the survivor, prior to breast cancer, many of whom were in traditional relationships; roles related to gender identity were the most salient: wife/partner, mother, daughter, sister, friend, etc. The salience might shift depending on who they were interacting with but they primarily identified with gendered role norms. Being diagnosed with a life threatening illness compelled breast cancer survivors to think about many issues related to breast cancer. The survivors were highly impacted by the threat of their death, as well as being sick and in pain. Whether it was a spouse, another family member or a member of a kinship group, most of the women had someone to assume their care giving responsibilities during the treatment phase of their breast cancer. As discussed previously, the period following the treatment phase was a critical one for the survivor. The loss of supportive medical care impacted the survivor across several domains. The survivors were still dealing with the physical and psychosocial aftermath of the diagnosis and treatment. Breast cancer survivors, faced with death, disability, as well as job loss, abandonment by friends and family and the existential issues of a life threatening illness, changed who they were and how they wanted to live, while others saw them as ready to resume their life as it was. The disease forced them to research and understand their illness, to find health care providers, make treatment decisions, cope with treatment effects, etc. As reported, many women saw breast cancer as having positive and negative meanings. Breast cancer survivors were renegotiating their identities but needed time to transition. In fact, they had the rest of their lives.

Some felt that they should embrace survivor as their identity. Other breast cancer survivors had difficulty with the term survivor because their ongoing symptoms and risk factors reminded them that survival was not a given. This placed them in a nether land of what Frank (1995) called the remission society, describing “all those people who … were effectively well but could never be considered cured” (p. 8). Survivors had experienced, and then continued to experience breast cancer; its treatments, resulting symptoms, and a formal release by health care providers back into life. However, life was no longer the same, nor were they. Breast cancer survivors thought of themselves as transformed and truer to themselves as a result of the sudden thrust into the medical system to procure care for themselves. They believed that they overcame the typical power and gendered responses of dealing with doctors and the medical system. In overcoming this, they reported that they learned to break from the constraining attitudes and behaviors that were typical of them prior to their diagnosis. Essentially, what women developed was a gender consciousness. The findings indicate that breast cancer survivors acquired a new commitment to self-interestedness: a sense that they needed to take care of themselves, they had a right to experience and enjoy life and be thoughtful of how they spent the rest of their life. Socialization into gender identities required that they be trained in empathy in order to have greater appreciation for others, especially loved ones. As caregivers, breast cancer survivors expressed the desire to give back. By doing so, they found empathy and understanding with those that shared their experience, which reinforced the gendered dimension of social interaction in everyday relationships, as well as within the context of breast cancer itself. This allowed them to connect with and form their new identities through relationships with like-minded others. This could result in role strain if the survivors were not impacted by gendered role consciousness.

Perceptual control.

Perceptual control in identity theory suggests a feedback loop system that occurs when an identity is set in motion. Identity verification is the desired result of matching self-perceptions in a situation to the identity’s standard meanings that the situation calls for. If unsuccessful, identity disruption occurs and one experiences negative emotions rather than verification. The intensity of the negative emotion is increased depending upon the relative salience or commitment that the breast cancer survivor has to the challenged identity (Stets, 2007). This was a significant issue for breast cancer survivors who felt permanently changed by breast cancer and could no longer maintain their previous identity.

Identity disruption (factors of the physical self).

The word cancer evokes feelings of fear, mortality, taboo, shame and silence. This is especially true in certain cultures, especially for African Americans and Latinas. Disclosure to potential partners, and reservations about dating was a major concern for some single African Americans, Latina and Asian Americans and resulted in a disruption to identity. This disruption to identity was imposed by the cultural meaning of stigma in the above populations.

However, the historical meanings of socialized silence in the African American community cannot be overstated. Many African Americans experience the unique impact of socialized silence as a result of the historical context of slavery, and health care atrocities visited upon them, both past and present. This includes the Tuskegee syphilis experiments of the 1940s through the 1960s and the more recently exposed case of Henrietta Lacks (Skloot, 2010). These were two of many incidents that blatantly hid the consequences to the participants and failed to obtain informed consent for these experiments from the participants and their families. This led to the cultural dynamic of socialized silence for which African Americans, specifically women survivors of breast cancer.

African Americans internalized the imposed socialized silence into a means of protection and rebellion against those that marginalized them. African Americans have been part of and separate from the American society for decades, which has led to both strengths and distrust. This provided a structural support that is unique to the African American society and resulted in identity outcomes that differed accordingly. The African American study participants spoke about reliance on community and social networks, strong spiritual beliefs and a cultural tradition of surviving severe obstacles as leading to positive outcomes with regards their identities as survivors.

All breast cancer survivors had difficulty with body image to one extent or another. African Americans, Asian Americans and Latinas thought that this was particularly an issue for younger survivors who were more concerned with body image. They also felt it might impact their ability to have a future relationship with a man. African American women viewed themselves as independent and white women as overly dependent on their men. The African American women expressed that they would not allow their men to determine what treatment course they chose based on body image. Again, this reflects differences amongst Caucasian and African American relational networks. African American breast cancer survivors also spoke about the fact that their breasts could not think or make choices, and therefore breasts did not fit their definition of being an attractive Black woman. Beauty was found not in breasts, but in a woman's mind, reflecting a differing social construction of feminine beauty. Married women felt less challenged by body image when their partners indicated that they loved them no matter what. Older women had fewer issues with body image but it did impact all women in one way or another. This was, for the most part, a disruption to self and created disappointment and sadness of the loss of the body as normal. However, the sense of shame and embarrassment could be also attributed to others, their partners, husbands and for those conceived of by those with no present partners but who would have to deal with body image in the future. The salience of relational networks to the breast cancer survivor was evident, and the resulting role strain was not unexpected.

The findings indicate that breast cancer survivors struggled with sexual issues due to treatment such as surgery or chemotherapy and radiation, each of which impacted and/or was impacted by sexual desire, problems with performance and physical limitations that were painful. These were disruptions that were based in the body but impacted both body and body image and created an identity disruption of self as a sexual being. Women spoke about the fact that health care providers did not prepare them for the sexual issues related to treatment. There was a sense of the spoiled body creating the spoiled identity. The women in the studies reported that there were many reasons to use measures that mitigate the spoiled identity, such as reconstruction. For example, a breast cancer survivor did not want to look different at work. She did not want her breast, or lack of it to be the focus. However, there were other reasons why women choose to have radical mastectomies on both breasts, as pre-emptive protective surgery or political statements. Still others used this as an opportunity to enhance their body. The issue of surgery and reconstruction has been discussed previously, in the section on emotion work. In this case, however, the survivor is dealing with identity work. Once again, the interrelatedness of these domains is evident. Women said that they were taken by surprise by physical symptoms such as pain that they thought might be a sign of recurrence. Some of the women felt hypochondriacal calling or visiting health care providers while others did not want to ruin relationships with health care providers and deferred calling. The unique aspect of the doctor-patient relationship was evident here, as the breast cancer survivors at once assumed the role of the compliant patient and dependent woman as a gendered role.

Identity disruption (factors of the psychosocial self).

The breast cancer survivors experienced psychosocial disruptive events, some of which were episodic and infrequent, and others that were on-going and frequent. These disruptive events imposed significant role strain upon the survivor as they attempted to manage their changing roles within a given social context. The pressure to be inauthentic was greatest during the time following the end of treatment. The nexus of relationships, both at home and abroad, expected them to behave as if they were once again normal, or to take on the role of the hero and be strong for others. The on-going nature of symptoms and fears of recurrence were at odds with this expectation and resulted in a significant source of distress, loneliness and alienation for the breast cancer survivor.

Another source of strain was related to gendered role expectations. Breast cancer survivors were faced with the need to renegotiate their identities as they shifted from the socially accepted norms of the self-sacrificing, empathetic, emotionally sensitive and nurturing care-giver, to an individualistic and more self-interested care receiver. This transition, although necessary as a coping mechanism when faced with a life-threatening condition, became an on-going struggle in the process to construct a renewed identity.

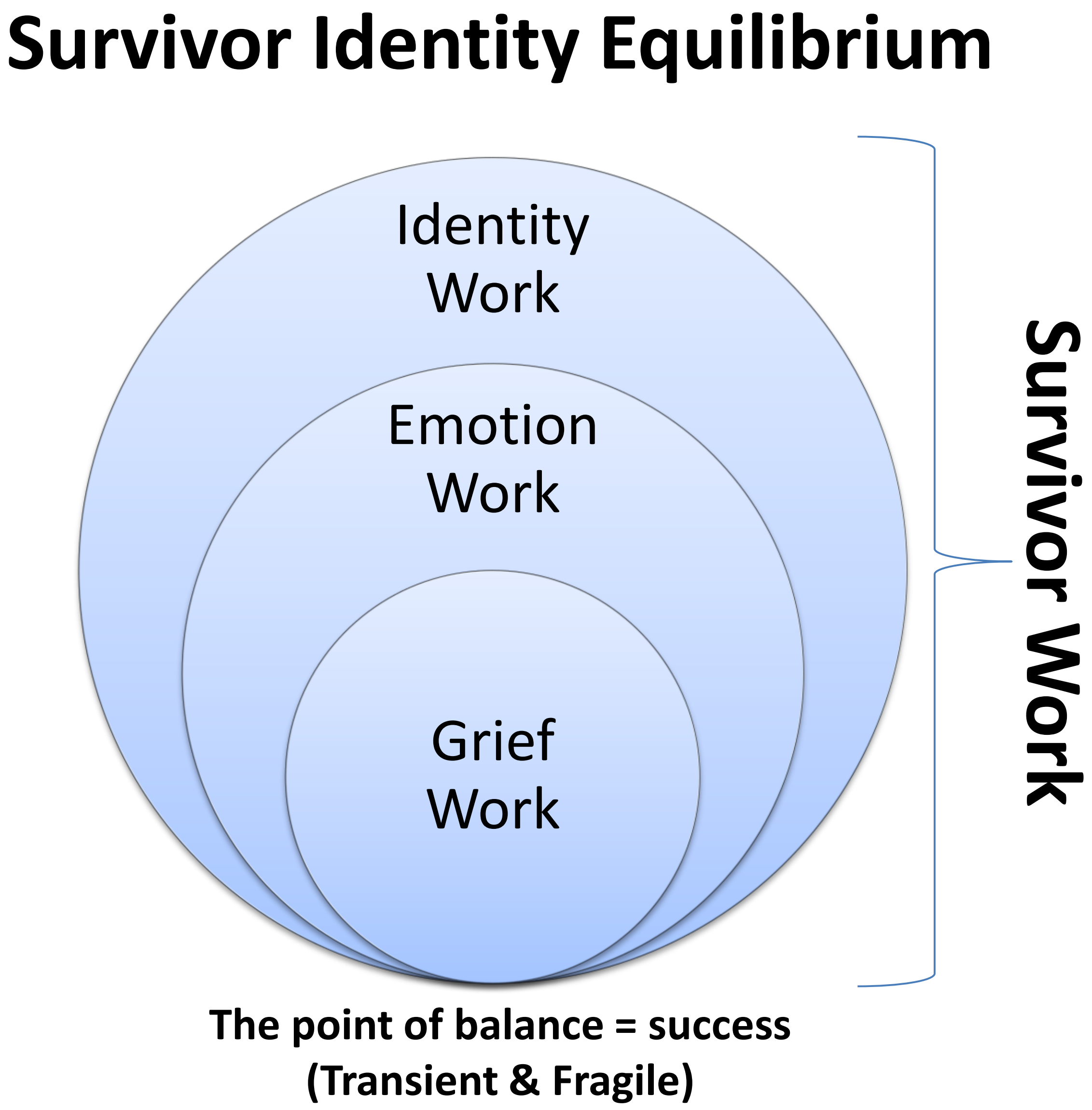
Similar disconnects between expectations and experience existed within the doctor-patient relationships and other interactions with health care providers. In this case, the breast cancer survivors were faced with an added dynamic of power differentials that intensified the gendered role conflict and led to feelings of distrust and loss of control, resulting in guilt and self-blame.

However, the process of discovering a renewed identity was not all negative. As the breast cancer survivors dealt with the life changing nature of breast cancer, positive reappraisal oftentimes emerged. The pre-cancer life no longer existed, replaced by deterministic attitudes and a renewed appreciation for life and living.

Survivor identity equilibrium.

As described previously, the theoretical framework of survivor work, leading to a new survivor identity contains three intersecting domains: emotion work, grief work and identity work. These domains are fluid, dynamic and shifting. The work within each domain is at the same time significant, ongoing and interrelated. Success occurs when balance or equilibrium is achieved at the intersection of the three domains. However this point of equilibrium is transitory at best. The focus of the work may not be equally distributed based on the individual survivor's salience of identity roles, emotional attachments, accomplished grief work, and the external physical and psychosocial disruptions and, of course, the cultural dynamics specific to age and ethnicity. The dynamic tasks of doing breast cancer involves many processes that will impact how breast cancer survivors negotiate their new identity of breast cancer survivor through emotion work, grief work and identity work. The thoughts, feelings, and meanings are impacted by the strain between and with breast cancer survivors and the conceptualizations of others in their lives of what it means to have breast cancer. The notion that breast cancer ends after treatment dismisses the reality of the ongoing physical, emotional and psychosocial effects that most, if not all, breast cancer survivors experience. It is not a static measure that begins and ends but one that is variable due to the impact of triggers, events, and physical manifestations that remind breast cancer survivors of the experiences and issues related to having breast cancer. Breast cancer has high visibility in popular culture due to the high rates of breast cancer and strong campaigns for research and other support. Popular culture can be a source of validation and/or annoyance for the breast cancer survivor and it can reinforce the notion that breast cancer is an event that ends with treatment. It does not address the ongoing issues related to having breast cancer. Though many survivors can negotiate a peaceful resignation of having breast cancer and achieve a somewhat balanced survivor identity (see Figure 10), a trigger such as a mammogram, physical symptom or an anniversary date related to the breast cancer experience, can easily skew the balance. Conversely, others appear to never quite achieve integration, or balance in their identity. It was also not clear from the findings whether the survivor identity is an ultimate identity, or one that is a step along a path to a higher level of integration.

Figure 7: Survivor Identity Equilibrium



Unique meanings across cultures.

Though breast cancer has many shared meanings across cultures, e.g. the shock, the fears, the gendered role expectations, etc., there are unique meanings and practices across cultures that impact the strength and path of balance.

African American

For instance, African American women possess a unique perspective of the health care system and of their ability to manage whatever happens, as well as a strong survival instinct. This is based on a history of overcoming horrific treatment, spiritual strength and sense of sisterhood developed in reaction to being the least privileged of the underprivileged. Non-family members that were part of African American breast cancer survivor kinship groups provided care for many survivors when there was no family or family was unable to provide support due to poor coping skills. Across the studies, African Americans reported more fatigue than other groups. In spite of the statements that some African Americans made about how they would tell men who had a problem with the survivors' bodies to move on, others reported concern about disclosing their illness. However, many African American women worked throughout the treatment phase of their breast cancer and maintained their care giving of others. Though African American breast cancer survivors reported on the silence and taboo related to cancer, many of them became ambassadors of information about breast cancer to other women. They spoke about the importance of exercise and the hazards of self-medication and herbal treatments. Many reported unequal treatment by health care providers and many had issues of access to proper care due to structural issues of lack of insurance and most disturbing, disrespectful treatment and marginalization of their concerns. Resilience and support is best illustrated in this community within and outside of support group settings.

Latina American

In the Latina community access to care was a significant issue. In some cases, it was related to immigration status and/or lack of or limited health care insurance. Latina breast cancer survivors expressed negative relationships with health care providers, who dismissed their concerns. The data revealed that the taboo associated with cancer, led the Latina survivors to remain silent about their breast cancer and possibly not seek treatment. Latina breast cancer survivors also kept working throughout treatment and some changed or discontinued treatment to retain their jobs. Others eschewed treatment due to the fear of losing their husbands as a result of a ruined body. This was not an empty fear since, as reported in the data; seven of the husbands abandoned their wives after diagnosis. This group expressed little desire to be in a relationship again.

The Latin culture endorses strong gendered distinctions for women and men. The concept of marianismo is a characteristic of the ideal women as a reflection of the feminine passivity and sexual purity, someone who is pure and giving. Interestingly, the male requires this of his wife and the mother of his child. Machismo, on the other hand allows him autonomy and therefore he is free to have romances with other women (Stevens, 1973). These cultural expectations compel Latina breast cancer survivors to continue to perform their roles even when they are not well. This was the only group not to report a decrease in sexual desire, which may be due to the social barrier of discussing sexual practices in other cultures. Additionally there is a strong taboo associated with breast cancer; it is difficult to freely express their feelings and therefore many did not disclose or discuss their diagnoses with neighbors. However, support groups for this population were very successful in providing a place to air their grievances and issues with other breast cancer survivors with similar cultural meanings.

Asian American

The most commonly diagnosed cancer for Asian American women is breast cancer. It is the leading cause of death for Filipino women. Japanese-American women have the highest breast cancer rate among Asian-American women. These rates are not similar to those of the corresponding countries of origin for Asian women. This may indicate that the American diet and lifestyle contributes to the higher cancer rate. However, another critical factor for Asian American women is that “compared to all other women in the United States, Asian-American women are the least likely to have ever had a mammogram. Getting a mammogram regularly is the best way to find breast cancer early, when it's easiest to treat” (WomensHealth, 2010).

Asian Americans, like Latinas have similar meanings within their cultural group that varies based on the continuum of acculturation. The more acculturated to the American culture the less one is likely to adopt the culture of origin’s meanings and/or the less strength those meanings possess. However, culture does impact meaning and there is a taboo associated with cancer that haunted the Asian American breast cancer survivors mostly via their female relatives’ pronouncement of death sentences. Asian Americans educated themselves about breast cancer and felt that being informed helped their relationship with health care providers. Most reported positive relationships with their health care provider. The Asian American population had fewer problems with monetary issues but language was a barrier for some of them.

Caucasian American

Caucasian breast cancer survivors had more access to care, were more positive about relationships with health care providers and talked more about fighting the illness and expressed an attitude of survival. They were also proactive and involved in their treatment and care. Caucasian breast cancer survivors were more concerned about incapacitation and autonomy than death and expressed disappointment that their healthy life style did not protect them from breast cancer. Some Caucasian breast cancer survivors reported discriminatory treatment due to a lack of financial ability. Others reported lack of support of family members due to poor coping ability but stressed the importance of support groups. They identified their husbands as their greatest support. Although all of the groups spoke about spirituality, Caucasian breast cancer survivors were less likely than the other groups to be a part of organized religion. Instead, they incorporated broad spiritual behaviors such as mindfulness as their means of spirituality and said that they were aware of the impact of stress as well as positive attitudes on health and healing.

Limitations of the Study

One of the limitations of this study was also its strongest asset and had to do with the researcher as an instrument and resulting possible unexplored biases. Russell and Kelly (2002), state “reflexivity is typically represented in the literature as a process of self-examination that is informed primarily by the thoughts and actions of the researcher” (p. 4). It is also an inescapable conclusion that the values and interests of the researcher is an integral factor in the production of research (Porter, 1993). Researcher bias may have been further influenced by the fact that the researcher performed both quality appraisal and data synthesis without the benefit of an additional second reader of the included and excluded articles. However, the strategies for its implementation which included the completion of self-reflective records and diaries, the examination of personal assumptions and goals, and the clarification of individual belief systems and subjectivities (Ahern, 1999) were addressed at other stages of the process. The goal of these activities was "to turn the researcher's gaze back upon oneself for the purpose of separation and differentiation" (Hawes, 1998, p. 100) and in this manner, reflexivity serves to improve the quality of the research (Barry, Britten, Barber, Bradley, & Stevenson, 1999). This was adequately addressed.

Furthermore, it is not unusual to list one reader as a limitation of a dissertation due to financial constraints. An informal inquiry of dissertations in the recent past has demonstrated that many included a single reader, the PhD candidate, and included this as a limitation of the study. The social sciences are utilizing qualitative research syntheses as an emerging methodology especially for policy. This may require adjustments to the process especially due to differing criteria across academic institutions and departments. This was demonstrated in Anderson (2008), a PhD candidate at the University of Alabama at Birmingham, when she used a process to mitigate the departmental and/or monetary limits of a one-author dissertation. Her process adjustment involved a random selection of approximately 30% the selected studies and re-read, re-rated as a confirmation of their inclusion. She then used a regression analysis “as a tool to check for accuracy and consistency of results” (p 28). All of the selected studies were read, reread and read many times over, and were re-rated as deemed necessary. Adjustments were made as the researcher progressed in the process and more information provided the need for adjustments.

Another consideration is the lack of generalizability of the study. This was dependent upon the nature of the data selected as a result of the research synthesis. However, this study is more concerned with depth and meaning than generalizability (Creswell, 2007). Similarly, though this study addresses these concepts across cultures, it does not signify an authoritative representation of these concepts for each cultural group studied. The Caucasian culture was most problematic in that there were limited studies that were specifically related to Caucasian breast cancer survivors whereas the other cultures were more studied. However, it is possible that there are other categories that may be more representative for certain participants based on factors such as socio-economic status, level of education, or age.

Ethical Considerations

The researcher did not foresee nor did she experience, any major risk for participation in this study. There were no resulting ethical considerations due to the inherent nature of a qualitative research synthesis which does not involve human subjects.

Policy Implications

The research suggests that the experience of having breast cancer has lifelong consequences for breast cancer survivors, including the impact of emotional, financial, physical, psychological, social, sexual, spiritual and cultural factors. These may further serve to hinder the successful integration of the survivor identity. Policy changes are necessary, and should include institutional and structural policy changes, as well as interventions and strategies that address the gaps in available services and service delivery. Specific areas follow.

Health care access.

Though many Americans believe that the U.S. health system is the best in the world, there exist studies that paint a far different picture. In an analysis that focused on the health data in Australia, Canada, Denmark, France, Germany, Netherlands, New Zealand, Norway, Sweden, Switzerland, the United Kingdom, and the United States, the following issues were highlighted:

> Among the 12 countries, the U.S. differs markedly on a number of health system measures. Health care spending in the U.S. in 2008 towered over the comparison countries, both per capita and as a percentage of gross domestic product (GDP). The U.S. had a comparatively low number of hospital beds and physicians per capita, and patients in the U.S. had fewer hospital and physician visits than in most other countries. However,

> hospital spending per visit was highest in the U.S. Prescription drug utilization, prices, and spending all appeared highest in the U.S., as did the supply, utilization, and price of diagnostic imaging. … With regard to quality, U.S. performance on a limited set of measures was variable. … These findings suggest that the U.S. health system is not delivering superior results despite being more expensive, indicating opportunities for cross-national learning to improve health system performance (Squires, 2011, p. 2).

A cross-national health care organizational summit with industrialized countries would indeed provide a much-needed perspective on cost vs. benefit of various health care options. However, a U.S. national health care system that provides health care for all should be a priority. The five-year survival rate for breast cancer in the U.S., at 93% for Stages I thru III (National Cancer Institute, n.d.), is certainly respectable and deserves notice, however there are other factors that have not been adequately considered and could address access to medical care across cultures. Early detection seems to be most important, in terms of survival. Programs that are culturally competent in that they are each staffed by same-culture trained breast cancer survivors are necessary. Locations that are easily accessed and situated in neighborhoods that reflect the culture receiving the services are a good solution to increasing the possibility of early detection and culturally competent partners. The negative impact upon outcomes without a national health system is glaring. The concerns of those that see this as a move towards more big government interference fail to recognize that policy within the present health care system, or lack of it, is being handed over to the very “institutions within the health care system – hospitals, insurance companies, and health maintenance companies- whose profit orientation prompts them to ration care…” (Blau, 1999, p. 180).

Of course, the impact of policy that excludes health care to all is greater for those who are the most vulnerable, those who lack financial means and/or health care insurance, but certainly this has a large impact for all of us. When one considers the cost of covering the uninsured via public versus private programs, the resulting impact is less than 1% of GDP. The overall impact of universal coverage on total health care costs would be an increase of 3-6% in total health care spending in the U.S., less than the annual inflation in health care spending (8.7% in 2001) in the current health care system, while creating a healthier society at a slightly higher cost. The impact of a healthier society where people can be treated sooner rather than later, or not all, as opposed to the looming issues that lack of health care and possible financial devastation pose, may further reduce the financial and social costs to American society (Kaiser Commission, 2003).

Transitional care planning.

In countries that already possess national health care, such as Canada, Denmark, Sweden, Australia and Europe (especially the United Kingdom), research supports the need for transitional care from specialist(s) to primary care practitioners and has been incorporated into the system (Smith, et al, 2011; Donovan & Vaile, 2009). In Denmark, a transition plan was created using a model of cooperation and transition of specialists to primary care physicians for patients with various types of cancer (Nielsen, Palshof, Mainz, Jensen & Olesen, 2003). This included a written survivorship plan of: active patient involvement; knowledge transfer from the specialist to the primary care physician and; availability of, and information for, open communication channels. This lowers costs while maintaining oversight and quality care to patients.

The emerging research related to breast cancer survivors in the United States, suggests feelings of abandonment and loneliness by the survivor after being released from the specialists' care, which echoes the concerns of the international survivors. The post-treatment period is an especially difficult time, during which the breast cancer survivor experiences residual pain and other triggers that exacerbate fears, primarily fears of recurrence (Burg, Lopez, Dailey, Keller & Prendergast, 2009; Lin & Donehower, 2010; Miller, 2007). The breast cancer survivor's negative reaction is not simply a psychological reaction but one resulting from the betrayal by their body and the loss of a relationship of trust and reliance developed with the oncology specialist and support staff. While there is concern amongst primary care physicians that transition plans may result in increased burden upon their practice, studies from Europe report that the transitions to primary care physicians or generalist practitioners do not translate to increased visits or telephone calls (Guilliford, et. al., 1997). In fact, Glynne-Jones, Chait and Thomas (1997), report that this model of transition was successful due to the specialists formulating a formal discharge system from their care to the primary care physician's care. Survivors were counseled and received a written contract reaffirming a good prognosis and assurance of the specialist's continued commitment to them when necessary. Primary care physicians received the discharge plan. The researchers noted that early communication with patients regarding specialist's follow up and duration of care, along with assistance in managing the anxiety of the transition, addressed the patient expectations, and made for a successful transition.

Culturally competent care.

Culturally competent health care must be included to serve the most vulnerable populations who may lack financial support, and have other issues related to language, access to proper treatment, and structural issues including payment systems, imbedded in the United States present health care delivery system. However, even with a comprehensive national health care policy, cultural competence must have a large role in providing equitable and proper care.

The disparities in survival rates in cancer, particularly breast cancer across socioeconomic groups, which intersect with culture and gender, are significant.

> Socioeconomic factors such as poverty, inadequate education, and lack of health insurance appeared to be far more important than biological differences. In 1991, Dr. Samuel Broder, then-Director of the U.S. National Cancer Institute declared, ‘poverty is a carcinogen.’ In practice, the elimination of disparities is defined as a reduction in cancer incidence and mortality and an increase in cancer survival among socioeconomically disadvantaged people and people historically targeted for prejudice and discrimination to levels comparable to those in the general population (as cited in Ward, Jemal, Cokkinides, Singh, Cardinez, Ghafoor, & Thun, 2004, p. 78).

Information from U. S. Cancer statistics further highlights the cultural issues that require policy changes. Both Latinas and African Americans were most impacted by the issues of access to health care and spoke about these issues with health care providers.

Latinas who are less acculturated may maintain cultural norms from their country of origin, such as lower age at first pregnancy, number of children and breast-feeding, all of which lead to lower incidence of cancer compared to non-Hispanic Whites. These factors do not protect them from being diagnosed with breast cancer at later stage of diagnosis with a 20% death rate as compared to non-Hispanic Whites (Jemal, Siegel, Ward, Murray, Xu, Smigal & Thun, 2006). This may be due to access to care, particularly culturally competent care, which addresses erroneous cultural meanings about screening, and other interventions (Bigby, 2005). This would benefit the breast cancer survivor as well as the family who may ascribe to long held cultural meanings that see breast cancer as a death sentence and a taboo, especially as it applies to the concepts of machismo and marianismo.

As previously noted, African Americans have a particularly heinous history of health treatment and/or lack of it. This has brought to attention the blatant disregard for patient information and consent on the part of the healthcare system at large. These are only a few of the numerous examples of healthcare disparity, racism and violation of trust, resulting in a culture of distrust and suspicion of the healthcare system by the African American community.

Asian Americans appeared more likely to have the financial means for treatment. Asian Americans also tended to follow doctors' orders due to the cultural value attached to education and to the doctors' elevated place in society. However, while strong in patient compliance, Asian Americans were also more likely to seek culturally specific alternative medical processes. As demonstrated by Fadiman (1999), the failure to have a translator, who understood cultural meanings and practices, resulted in consequences for the patient and family that were devastating.

Betancourt, et al. (2003), in the Meta Summary titled "Defining Cultural Competence: A Practical Framework for Addressing Racial/Ethnic Disparities in Health and Health Care" provide an excellent case for culturally competent care and the challenges that minorities face. They identify sociocultural barriers at the "organizational (leadership/workforce), structural (processes of care) and clinical (provider-patient encounter) levels" (p. 293). This study speaks to the issue of ongoing segregation in the healthcare system, and proposes steps to re-invent the struggle for parity that could be addressed in the context of a National Health Policy (Smith, 2005).

Organizational barriers.

Betancourt, et al. report that African Americans, Latinos and Native Americans make up a mere 3% of the total of health care leadership and only 2% of senior leadership roles despite representing 28% of the U.S. population. This lack of diversity in the senior leadership of health care providers results in "structural policies, procedures, and delivery systems inappropriately designed or poorly suited to serve diverse patient populations" (2003, p. 296). Conversely, minority professionals meet the needs of minority patients by creating systems that match their life and work patterns, such as extended hours of service and intake practices that encourage the undocumented to seek medical care. Additionally, both Hispanic and African American physicians accommodate a larger percentage of patients with Medicaid as the primary insurer, and many of these professionals understand the challenges of the communities they serve because they have lived it themselves. Satisfaction is highest, when minority patients are served by minorities in the professional and extended health care workforce.

Structural barriers.

Furthermore, research suggests that bureaucratic and complex medical systems are underfunded and archaic, and present special challenges to minorities (Betancourt, et.al, 2003). These include: language barriers that lead to a lack of understanding of patients' diagnosis and treatment, medication instructions, and follow up care. Minority breast cancer survivors also face barriers that discourage them from seeking medical assistance when necessary, and from utilizing specialists for continuum of care. These barriers impact health seeking and successful health outcomes. This requires more and relevant training in cultural competence. Additionally, more positions must be filled by those whose gender, language and culture reflects that of the breast cancer survivor.

Clinical barriers.

Clinical barriers occur when the disparity between the cultural understanding of the health care provider and the patient result in an ineffective interaction between the two. A culturally diverse society, as represented in the U.S., presents a special challenge to a healthcare system, and the health care providers within it, that lack a similar cultural diversity, as discussed previously. Though many of the cultural issues were identified in the articles selected for this qualitative research synthesis, other cultural issues should be explored further, with potential policy implications. For instance, as previously mentioned, the categorization within each distinct cultural group is typically presented as being homogenous. For example, although Asian Americans share many common and basic cultural meanings, within the Asian American culture, diet and lifestyle choices differ widely. This affects a first incidence of breast cancer, as well as the risk of recurrence. This is true of Hispanic groups as well. Future studies should target research within these distinct groups.

Age / sexuality related barriers.

Another area identified for policy change is to address the differences of older vs. younger breast cancer survivors and single vs. those with life partners. Younger breast cancer survivors are faced with issues related to their sexuality, sexual performance, desirability, and ability / inability to have children, and therefore often are considered as not being a viable partner (Thewes, et.al. 2004; Porter, 1993). Some of these issues are more relevant for single breast cancer survivors and might also be more of an obstacle for the less acculturated, due to culturally specific role expectations for women to marry and bear children. Each component of these breast cancer survivors should have access to individual and group counseling. Survivors, who have experienced these concerns and have overcome the challenges, should be given an opportunity to share their experiences and successes in various settings, both individually and in groups.

Older breast cancer survivors also face sexual issues but may have more pre-existing health issues that exacerbate their quality of life and recovery time. Older single women may be more isolated than survivors with significant others, and may have less access to support systems that can provide assistance in decision-making. This again presents an opportunity for breast cancer survivors further along in their survival to talk about life after breast cancer. That, along with the appropriate health care provider to help them to identify the issues and present options for treating and managing them would greatly improve service delivery to this group of survivors.

On a wider level, research regarding survivors, particularly for older, long-time survivors whose issues are compounded by age related illnesses and the usual physical issues that aging brings is necessary. This group can be served, not only by the relevant groups listed above, but the many community groups available for senior citizens that can provide further support and links to services with little or no additional cost. Programs by service groups for the elderly, such as local senior groups, Meals on Wheels; Catholic Charities; Lutheran Services and other faith-based organizations are examples of this type of support. Generally, hospitals and medical centers that offer medical services should consider the psychosocial challenges as part of their responsibility in their role as healers. A good transition plan can address these issues for the younger and older breast cancer survivors.

Sexual orientation.

One final area that requires more research is the impact of experience and meaning of breast cancer for the Lesbian, Gay, Bi-Sexual and Transgender population. The literature specific to this population as regards breast cancer is sparse and was only indirectly referenced in the literature reviewed for this study. Though not as isolated as in the past, this is a group that is more vulnerable to breast cancer due to higher rates of risk behaviors such as smoking and alcohol use and a tendency to nulliparity (the condition of being nulliparous, or not bearing offspring) (The SafeGuards Project & LGBT Health Resource Center, 2003). Additionally, the American Cancer Society (n.d.) reports that the risk of breast cancer after male to female transgender surgery and Hormone Replacement Therapy may increase after 5 years, inferred by similar statistics for the same therapy use in non-transgendered women. Additionally, excessive testosterone in non-transgendered men and in female to male transsexual men can be converted to estrogen and may lead to breast cancer and/or other health problems. Support groups and other breast cancer survivors that reflect the particular lesbian, gay, bi-sexual or transgender person, as well as medical personal that serve this population should be available for treatment and support.

Payment systems.

For the purpose of this discussion, a distinction must be made between a health care practitioner, and a primary care physician The term health care practitioner is used to describe the larger population of medical professionals, including specialists and primary care physician. The term primary care physician is used to describe the subset of practitioners that provide general medical support to their patients. The type of payment structure that a health care practitioner accepts may lead to recommendations that do not provide the appropriate medical interventions. This may be exacerbated in the case of minority and disadvantaged populations. Decisions and / or recommendations may be influenced in favor of increasing income for the health care practitioner by ordering unnecessary interventions / tests (increased revenue), or by a reluctance to treat patients who have pre-existing conditions (reduced costs). Issues exist related to the reluctance of primary care physicians to take on the responsibility of caring for someone who may require continued and specialized care and hand holding as compared to other patients.

There are structural reasons for this reluctance. Healthcare payment systems basically take one or more of the following three forms of payment arrangements between health plans and physicians: 1) fee-for-service, 2) capitation, and 3) salary (Gaynor & Mark, 1999). Each of these plans may influence the decisions that health care practitioners make based on the opportunity for increased income and accordingly have consequences for the patient.

Fee for service.

According to MedicineNet.com (n.d.), fee for service is defined as: "…a payment mechanism in which a provider is paid for each individual service rendered to a patient." (p. 1) This may encourage abuse of the system since health care providers generate more income when their patients receive additional services and/or more costly services. In this scenario, the risk is assigned to insurance companies, rather than to the health care provider or the patient. Goodson, Bierman, Fein, Rask, Rich & Selker (2001) state that "In fee-for-service practices, physicians tend to order more tests, consultations, elective procedures, and hospitalizations. When physicians have ownership of consulting services, their rates of utilization of these ancillary services are higher" (p. 250).

Some argue that health care providers need this level of autonomy in making these decisions. Many dangle the threat of socialized medicine as a poor option. However, the abuses that fee for service elicits caused Dr. Marc Feldman, a medical academic from Britain who spent time in the U.S., to make a compelling case for a more equitable system. He praises the American medical system for quality healthcare, especially in cancer care, as well as in academic biomedical research. However, he points to "problems on a huge scale, which means that the U.S.'s world-leading health expenditure (16% of GNP) is delivering health care that is worse than in much of Europe in terms of clearly analyzable indicators, such as infant mortality or length of life. European countries like the UK typically spend 8%–10% of GNP on health care…" and he rightfully mentions the "lower-percentage cost of health care in Europe covers all the population, while the U.S.'s 16% still leaves 45 million uncovered" (Feldman, 2009, p. 2861).

Capitation.

Capitation may better serve patients who are healthy vs. patients who require more extensive care, or have pre-existing conditions. Why? The modality of capitation is such that a health care provider assumes the most risk in that they receive one payment for each year for each patient. These health care providers have a pool of patients, much like insurance pools, and the health care provider (and indirectly the patient) assumes the risk of the outcome. In a capitation fee system, the health care providers are betting that of the large pool of patients, some will require little to no care, many will need some care, and they hope that few will require intensive care. If that is the case, they will be paid for treating a low to moderate number of patients. Many believe that this is a disincentive to see patients and provide appropriate care and testing, especially if the patient has difficult and/or pre-existing conditions, such as in the case of the breast cancer survivor. Existing studies reveal that health care providers under fee for service payment system provided more care and tests than under either capitation or salary fee structures. Other studies echo the issue of less care and tests with capitation. However, there were mixed reviews on salary (Gosden, Forland, Kristiansen, Sutton, Leese, Giuffrida, Sergison & Pedersen, 2000).

"Physicians in highly capitated practices had the lowest total costs and intensity of care…" (Landon, Reschovsky, O'Malley, Pham, and Hadley, 2011, p. 1863). This seems to be true for primary care physicians more than specialists. Additionally, Landon, et al. believe that “these physicians develop an overall approach to care that also applies to their fee for service patients” (p. 1863). Since most primary care physicians accept various means of payment, this study may demonstrate that a mixed payment practice may result in a moderation of the usual fee for service mode of service delivery and a compromise in service delivery.

Salary.

Salaried physicians, in contrast to either fee for service or capitation payment services, serve as employees of the health plan, and receive income that is constant and not effected by the amount of care provided. Typically, financial incentives are not available that would impact service delivery either positively or negatively.

Impact upon the woman survivor of breast cancer.

The impact on quality of care and service delivery to the breast cancer survivor varies from one fee payment plan to another. As indicated previously, this may be especially pertinent to minority and/or disadvantaged survivors. In the case of fee for service, the impact of higher medical costs is shared by the insurance companies and patients in general, due to higher co-insurance and policy premium costs. This may result in an additional financial burden to the breast cancer survivor, regardless of ethnicity, race or socio-economic status. Capitation, on the other hand, may result in a compromise in service delivery, which, of course, has a direct impact on the breast cancer survivor. Additionally, health care providers, and specifically primary care physicians may be reluctant to accept complex medical cases or those with compounded or pre-existing conditions, due to the added cost burden above the typical patient.

Recommendations for policy change.

The proposed policy would encourage the specialist to create a transitional care plan that includes the transfer of patients’ records, a schedule for mammograms, blood work, and recommendations for services, such as counseling, peer advocates and other follow-up care as deemed necessary. Similar to the transitions utilized by nurses and doctors for shift changes in a hospital setting, verbal communication is an important part of the transition. This takes time, which can be an issue for specialists and especially for primary care physicians, who already feel undervalued and underpaid. Nurses suggest that this be a team effort that includes nurses, specialists and primary care physicians (Lin & Donehower, 2010). This includes what is viewed as negative incentives related to non-reimbursement for this service (Miller, 2007). Policies must be in place to prohibit and investigate refusals to treat patients due to health history. Primary care physicians should be compensated for the extra care that they provide breast cancer survivors without financial burden to the survivor. As a nation, a state and an organization, discharge planning should include not only a list of services but also a comprehensive assessment of services necessary for a safe and smooth recovery at home. This should include follow-up by a social worker and/or a patient advocate via telephone and home visits to guarantee the proper post-surgery/treatment care.

Structural barriers, which affect patient and health care provider interaction, leading to ineffective communication, lack of patient satisfaction, and poor health outcomes, can be addressed by

a.) Translation services that pay specific attention to, understand, and are sensitive to the breast cancer survivors' cultural norms, including the preferred use of female translators;

b.) Targeted recruitment and training of more minorities in the health care professions and in supportive roles with funding in the form of scholarships, grants, etc. for minorities in health care at all levels. This can be best accomplished by various incentives to work with the most vulnerable populations, including loan forgiveness programs and grants;

c.) Protection for undocumented women who are breast cancer survivors by a no-reporting policy and by having flexible hours for appointments for survivors.

As previously stated, support groups mitigate the sense of isolation breast cancer survivors feel with families and friends, especially at the stage of survivorship when treatment has ended and survivors are in the nether land between the sick and the well. Some Survivorship Care Plans, Mental Health Counselors, organizations specific to cancer care support, such as "LIVE**STRONG**" (n.d.), as well as political advocacy groups recommend support groups to deal with the psychosocial issues that breast cancer survivors report. However, not all support groups are equal. Culturally specific support groups were identified as being successful and allowing the breast cancer survivor to form long lasting bonds with other survivors. Culturally competent care could be supplied by breast cancer survivors within the cultural groups to guide women of various cultures through the process of navigating their illness in a welcoming and familiar environment. This could include volunteers, as well as re-training or patient advocacy within the cultural groups in the helping professions. This training should encourage and include support groups that are culturally distinct and empower survivors to openly share with each other what they feel compelled to remain silent about, in general social settings.

Community based groups, held in community centers specific to each cultural group, and libraries with private meeting rooms, might allow for valuable no-cost settings. Spirituality achieved through religious observance was identified as important for all of the non-Caucasian groups studied; therefore church-based groups would be especially safe and comforting places for hosting groups and providing survivor information. For Caucasian populations, stress reduction through non-organized spiritual and holistic practices replaced organized religion. Many organizations and hospital-based groups already host culturally competent groups that provide information, as do local cancer specific organizations, such as American Cancer Society, the Breast Cancer Coalition and Cancer Care. Many of the above mentioned groups and organizations provide culturally competent individual counseling, as well as financial support, though it is limited and problematic for non-documented populations, whose access to support and care must be provided by non-government organizations that care about people regardless of origin or status.

Finally, this research highlights the ongoing issues with survival (including survivor work), which continue well after anyone, except for the survivor, recognizes it. Research that addresses long-term survivorship issues, implications, support and interventions is necessary to the ever increasing numbers of women survivors of breast cancer, as well as other cancer survivors.

Future Research

Future research should include less homogenous groupings to understand the differences within and between the cultures represented. For instance, the categories of Asian and Latina include various ethnicities with distinct lifestyles and cultural meanings and practices. This may impact the treatment and follow-up for breast cancer survivor care. Additionally, more studies that focus on specific age groups may help to understand the impact that age has on the survival experience and to identify necessary interventions and support within those groups. Another area of future research may be related to sexual orientation, and the specific issues that the Lesbian, Gay, Bi-Sexual and Transsexual populations experience. Research that focuses on the impact that breast cancer has on the family of survivors may inform policy that creates safe spaces for them to understand the breast cancer survivor’s experience and share their fears and needs. Research on the economics of breast cancer that explores the impact of financial status and need upon the quality of care and treatment interventions, as well as the resultant cost benefit is needed.

Conclusion

Breast cancer survival is a positive outcome of new and effective treatment and earlier diagnosis. However, breast cancer care has lifelong issues which require financial, medical, psychological and social support for breast cancer survivors and those in their lives. Due to long term survival, breast cancer survivors and their families will deal with the ongoing issues related to breast cancer survival along with the impact that breast cancer has on the survivor as they age. As the largest group of cancer survivors this poses a serious issue for health care and must be addressed in a compassionate yet economical way.

This study provides insight into the nature of the work of developing a survivor identity for women survivors of breast cancer. As a qualitative research synthesis, it draws data from sixteen qualitative research studies focused on breast cancer survival across African American, Asian American, Latina American and Caucasian American cultures. The analysis and resultant interpretation provides a basis for theory as to the path towards survivorship that the breast cancer survivor takes from the moment she is diagnosed. The journey causes her to face a number of psychosocial and physical factors, both internal and external, that result in a significant shift of the roles she has played prior to breast cancer, and are still challenged to play after breast cancer. The survivor often finds herself alone and misunderstood. Those who are closest to her expect her to move on with her life, and return to what once was, but she is constantly reminded, through every pain and symptom, media image, and negative news report that the sword of Damocles forever hangs over her head and life will never be the same. In the process of learning how to play these new roles, she finds herself negotiating a new identity … one of survivor. The negotiation involves the work of three distinct, and yet interrelated domains … emotion, grief and identity. The goal of this negotiation is to achieve equilibrium between the three, however, this is often an elusive goal, as the forces, events, interactions, etc., all conspire to disrupt this transient balance.

The study also examines the cultural impacts to the journey towards a survivor identity. While many of the internal / external factors and roles are shared across cultures, a number of differences were revealed, that became unique challenges for specific cultures. Issues such as socialized silence for African Americans, language barriers and degree of acculturation for Asian Americans, and the dynamics of marianismo and machismo for Latina Americans were explored. Additionally, the effect of access to good care based upon socioeconomic status was a shameful reminder of how race, class and gender impacts health and survival.

Policy change is recommended to provide improved support to the breast cancer survivor. This should include tailored transitional care plans so that the move beyond the acute (treatment) phase, to the re-entry and long-term survivor phases are smooth. Culturally competent care must be provided to address structural barriers that affect care for ethnic minorities. Support groups, both community-based and within the healthcare system, should become sensitized to the ongoing struggle for identity that every breast cancer survivor faces.

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Appendix A: Codes and Links

acculturation - cultural modification of an individual, group, or people by adapting to or borrowing traits from another culture

Links

<-- impacts --> identity work
<-- impacts --> thoughts

This code is present in 7 segment(s).

acute stage - encompasses initial diagnosis and treatment, which is usu-

Links

--- isa --> survivorship stage

This code is present in 22 segment(s).

adjuvant therapy - Additional cancer treatment given after the primary treatment to lower the risk of recurrance of cancer. Adjuvant therapy may include chemotherapy, radiation therapy, hormone therapy, targeted therapy, or biological therapy.

Links

--- may effect --> sexual function

This code is present in 6 segment(s).

African American - an American of African descent whose ancestors were brought to the U.S. by force

Links

--- isa --> cultural identity

This code is present in 111 segment(s).

altruistic pursuit - A pursuit which demonstrates a concern for the welfare of others.

Links

--- is part of the --> identity work
--- is part of the --> positive meaning
<-- isa --- giving back

This code is present in 7 segment(s).

Asian American - an American of Asian descent

Links

--- isa --> cultural identity

This code is present in 54 segment(s).

body image - a subjective picture of one's own physical appearance established both by self-observation and by noting or anticipating the reactions of others

Links

--- causes --> grief work
--- causes --> identity work
--- isa --> physical factor
<-- impacts --> thoughts
--- may effect --> wsbc's womanhood
<-- impacts --> feminine beauty

This code is present in 62 segment(s).

Cancer is a gift - A perspective that sees Cancer ultimately causing positive meaning.

Links

--- is part of the --> emotion work
--- causes --> positive meaning
--- isa --> psychological factor
--- isa --> spiritual factor
--- isa --> thoughts

This code is present in 3 segment(s).

Caucasian - of or relating to the white race of humankind as classified according to physical features. For the pupose of this study, an American.

Links

--- isa --> cultural identity

This code is present in 46 segment(s).

community member - member of a community. Community: an interacting population of various kinds of individuals in a common location

Links

--- isa --> wsbc identity role
<-- may effect --- giving back

This code is present in 18 segment(s).

concealing fears - Hidden thoughts ... non-verbalized feelings / thoughts.

Links

--- is part of the --> emotion work
--- isa --> expectations of others

This code is present in 6 segment(s).

concealing symptoms - Hiding symptoms, thoughts, physical / emotional.

Links

--- is part of the --> emotion work
--- isa --> expectations of others

This code is present in 6 segment(s).

concealing true feelings - Hidden feelings ... non-verbalized feelings. Keeping silent to please others or not to offend others.

Links

--- is part of the --> emotion work
--- causes --> socialized silence
<-- causes --- pressure to be a hero

This code is present in 4 segment(s).

coping mechanisms - A psychological strategy that involves expending conscious effort to solve personal and interpersonal problems, and seeking to master, minimize or tolerate stress or conflict.

Links

--- isa --> emotion work
--- isa --> psychological factor
<-- isa --- mindfulness
<-- isa --- taking control

This code is present in 18 segment(s).

cultural identity - An identity specific to a culture. Culture: the customary beliefs, social forms, and material traits of a racial, religious, or social group

Links

--- may effect --> identity work
<-- impacts --> thoughts
<-- isa --- african american
<-- isa --- asian american
<-- isa --- caucasian
<-- isa --- latina

This code is present in 27 segment(s).

distraction - diversion of the attention

Links

<-- impacts --> emotion work
--- isa --> psychological factor
<-- isa --- fear of recurrence

This code is present in 6 segment(s).

education - the knowledge and development resulting from an educational process

Links

--- may effect --> quality of care

This code is present in 5 segment(s).

emotion work

Links

<-- is part of the --- cancer is a gift
<-- is part of the --- concealing fears
<-- is part of the --- concealing symptoms
<-- is part of the --- concealing true feelings
<-- isa --- coping mechanisms
<-- impacts --> distraction
<-- impacts --> emotional support
<-- causes --- end of treatment
<-- impacts --> expectations of others
<-- impacts --> expectations of self
<-- impacts --> fear and guilt related to becoming a burden to others
<-- causes --- fear of recurrence
<-- impacts --> hcp sensitivity / communication
<-- causes --- increased role strain
<-- is part of the --- isolation
<-- causes --- language / communication
<-- impacts --> life changing nature of bc
<-- causes --- loss of control
<-- impacts --> loss of self
<-- is part of the --- mindfulness
<-- causes --- ongoing symptoms
<-- is part of the --- patient compliance
<-- causes --- pressure to be "normal"
<-- causes --- pressure to be a hero
<-- impacts --> quality of care
<-- is part of the --- self interestedness
<-- is part of the --- shift from caregiver to care receiver
<-- impacts --> social support
<-- impacts --> socialized silence
<-- impacts --> support groups
<-- is part of the --- uncertainty

This code is present in 0 segment(s).

emotional factor - a factor related to a conscious mental reaction (as anger or fear) subjectively experienced as strong feeling usually directed toward a specific object and typically accompanied by physiological and behavioral changes in the body

Links

<-- may effect --- fear of recurrence
<-- isa --- giving back
<-- may effect --- healthcare system
<-- isa --- loss of control
<-- isa --- mindfulness
<-- isa --- socialized silence
<-- impacts --> thoughts
<-- isa --- urgency of life

This code is present in 170 segment(s).

emotional support - the sensitive, understanding approach that helps patients accept and deal with their illnesses; communicate their anxieties and fears; derive comfort from a gentle, sympathetic, caring person; and increase their ability to care for themselves

Links

<-- impacts --> emotion work
--- isa --> resource

This code is present in 83 segment(s).

employee - one employed by another usually for wages or salary

Links

--- isa --> wsbc identity role

This code is present in 9 segment(s).

employer - one who employs another usually for wages or salary

Links

--- may effect --> expectations of others
--- may effect --> social support

This code is present in 2 segment(s).

end of treatment - the point in the continuum of care for the WSBC when initial and adjuvant treatments end.

Links

--- causes --> emotion work
--- is part of the --> identity work
--- may effect --> social support

This code is present in 24 segment(s).

expectations of others - The WSBC's perception or anticipation of what others expect of their (the WSBC's) behavior.

Links

<-- impacts --> emotion work
<-- impacts --> identity work
--- causes --> increased role strain
<-- isa --- concealing fears
<-- isa --- concealing symptoms
<-- may effect --- employer
<-- may effect --- family member
<-- may effect --- friend
<-- may effect --- health care provider
<-- may effect --- mother
<-- may effect --- neighbor
<-- isa --- pressure to be "normal"
<-- isa --- pressure to be a hero
<-- may effect --- wife or partner

This code is present in 15 segment(s).

expectations of self - The behavior that the WSBC expects of themselves.

Links

<-- impacts --> emotion work
<-- impacts --> identity work
<-- is part of the --- fear and guilt related to becoming a burden to others
<-- may effect --- self interestedness

This code is present in 16 segment(s).

Family member - A member of a group of individuals, possibly living under one roof and usually under one head

Links

--- may effect --> expectations of others
--- isa --> wsbc identity role

This code is present in 61 segment(s).

fear and guilt related to becoming a burden to others - not described in detail.

Links

<-- impacts --> emotion work
--- is part of the --> expectations of self
<-- may effect --- self interestedness

This code is present in 22 segment(s).

fear of recurrence - The fear that is connected to the possibility of reccurence of cancer based on historical data.

Links

--- isa --> distraction
--- causes --> emotion work
--- may effect --> emotional factor
--- may effect --> mindfulness
--- isa --> negative meaning
--- may effect --> psychological factor
--- may effect --> social factor
--- may effect --> thoughts
--- may effect --> uncertainty
--- causes --> urgency of life

This code is present in 18 segment(s).

feminine beauty - A socially constructed definition of beauty and femininity associated with the physical characteristics of a woman.

Links

<-- impacts --> body image
--- is part of the --> grief work
--- is part of the --> identity work
--- isa --> physical factor
--- may effect --> wife or partner

This code is present in 3 segment(s).

financial factor - A factor related to the management of money, banking, investments, and credit

Links

--- may effect --> social support
<-- impacts --> thoughts
<-- may effect --- healthcare system

This code is present in 22 segment(s).

Friend - A person whom one knows, likes, and trusts.

Links

--- may effect --> expectations of others
--- isa --> wsbc identity role

This code is present in 31 segment(s).

gendered role conflict - A gender related situation in which a person is expected to play two incompatible roles.

Links

--- causes --> identity work
--- may effect --> thoughts

This code is present in 13 segment(s).

giving back - Grateful giving based on a perceived or real sense of being the recipient of help, support, etc., or an extension of life.

Links

--- isa --> altruistic pursuit
--- may effect --> community member
--- isa --> emotional factor
--- causes --> positive meaning
--- isa --> psychological factor
--- is part of the --> support groups

This code is present in 5 segment(s).

Grief Work

Links

<-- causes --- body image
<-- is part of the --- feminine beauty
<-- is part of the --- healthy behavior
<-- is part of the --- isolation
<-- impacts --> loss of friendships
<-- is part of the --- mindfulness
<-- is part of the --- positive reappraisal
<-- impacts --> role conflict
<-- is part of the --- seeing life as being precious
<-- is part of the --- sexual function
<-- impacts --> socialized silence
<-- impacts --> stigma & disclosure
<-- is part of the --- taking control
<-- is part of the --- urgency of life
<-- is part of the --- wsbc's womanhood

This code is present in 0 segment(s).

HCP sensitivity / communication - not described in detail.

Links

<-- impacts --> emotion work

This code is present in 22 segment(s).

Health Care Provider - A medical professional.

Links

--- may effect --> expectations of others
--- is part of the --> healthcare system
<-- is part of the --- patient compliance

This code is present in 92 segment(s).

Healthcare System - the organization of people, institutions, and resources to deliver health care services to meet the health needs of target populations.

Links

--- may effect --> emotional factor
--- may effect --> financial factor
--- may effect --> social factor
<-- is part of the --- health care provider
<-- is part of the --- information
<-- isa --- language / communication
<-- is part of the --- patient compliance
<-- is part of the --- quality of care

This code is present in 23 segment(s).

healthy behavior - Behavior that may improve the health outcomes of a person.

Links

--- is part of the --> grief work
--- isa --> positive meaning
<-- impacts --> quality of care
--- may effect --> social support

This code is present in 24 segment(s).

Identity Work

Links

<-- impacts --> acculturation
<-- is part of the --- altruistic pursuit
<-- causes --- body image
<-- may effect --- cultural identity
<-- is part of the --- end of treatment

<-- impacts --> expectations of others
<-- impacts --> expectations of self
<-- is part of the --- feminine beauty
<-- causes --- gendered role conflict
<-- causes --- increased role strain
<-- impacts --> life changing nature of bc
<-- impacts --> loss of control
<-- is part of the --- loss of friendships
<-- impacts --> loss of self
<-- impacts --> ongoing symptoms
<-- is part of the --- positive reappraisal
<-- causes --- pressure to be "normal"
<-- causes --- pressure to be a hero
<-- causes --- role conflict
<-- is part of the --- self interestedness
<-- impacts --> sexual function
<-- is part of the --- shift from caregiver to care receiver
<-- impacts --> stigma & disclosure
<-- impacts --> support groups
<-- is part of the --- taking control
<-- is part of the --- urgency of life
<-- is part of the --- wsbc's womanhood

This code is present in 0 segment(s).

increased role strain - the stress or strain experienced by an individual when incompatible behavior, expectations, or obligations are associated with a single social role

Links

--- causes --> emotion work
--- causes --> identity work
<-- causes --- expectations of others

This code is present in 16 segment(s).

information - the communication or reception of knowledge or intelligence

Links

--- is part of the --> healthcare system

This code is present in 25 segment(s).

isolation - includes fellings of abandonment

Links

--- is part of the --> emotion work
--- is part of the --> grief work
--- causes --> loss of self
<-- causes --- social support

This code is present in 9 segment(s).

language / communication - related to the method of communicating information through verbal or written means, possibly in various languages

Links

--- causes --> emotion work
--- isa --> healthcare system

This code is present in 10 segment(s).

Latina - a woman or girl of Latin-American origin living in the United States

Links

--- isa --> cultural identity

This code is present in 65 segment(s).

life changing nature of BC - A phenomenon experienced by people with life threatening events, such as cancer.

Links

<-- impacts --> emotion work
<-- impacts --> identity work
<-- is part of the --- mindfulness
<-- may effect --- negative meaning
<-- may effect --- positive meaning
<-- isa --- sick role

This code is present in 14 segment(s).

long-term survivorship - refers to the period from disease-free survival through the years when likelihood of recurrence is low

Links

--- isa --> survivorship stage

This code is present in 10 segment(s).

Loss of Control - loss of the ability to manage or direct one's own life

Links

--- causes --> emotion work
--- isa --> emotional factor
<-- impacts --> identity work
--- may effect --> loss of self
--- isa --> negative meaning
--- is part of the --> patient role
--- isa --> psychological factor

This code is present in 10 segment(s).

loss of friendships - A change of relationship status from positive and / or active to negative and / or inactive.

Links

<-- impacts --> grief work
--- is part of the --> identity work
--- isa --> negative meaning
--- may effect --> social support

This code is present in 5 segment(s).

loss of self - a sense of loss of the union of elements (as body, emotions, thoughts, and sensations) that constitute the individuality and identity of a person

Links

<-- impacts --> emotion work
<-- impacts --> identity work
--- isa --> negative meaning
--- isa --> psychological factor
<-- causes --- isolation
<-- may effect --- loss of control

This code is present in 14 segment(s).

marriage and children - not described in detail.

This code is present in 3 segment(s).

mindfulness - the quality of being fully present and attentive in the moment during everyday activities (living in the moment).

Links

--- isa --> coping mechanisms
--- is part of the --> emotion work
--- isa --> emotional factor
--- is part of the --> grief work
--- is part of the --> life changing nature of bc
--- isa --> psychological factor
<-- may effect --- fear of recurrence
<-- impacts --> seeing life as being precious
<-- may effect --- urgency of life

This code is present in 2 segment(s).

Mother - a female parent

Links

---	may effect	-->	expectations of others
---	isa	-->	wsbc identity role

This code is present in 8 segment(s).

Negative meaning - A meaning which lacks positive qualities. It is derived from the negative responses WSBC have to the physical, emotional, social and psychological effects of the BC diagnosis.

Links

---	may effect	-->	life changing nature of bc
---	isa	-->	psychological factor
<--	isa	---	fear of recurrence
<--	isa	---	loss of control
<--	isa	---	loss of friendships
<--	isa	---	loss of self
<--	causes	---	ongoing symptoms
<--	is part of the	---	pressure to be "normal"
<--	causes	---	sick role
<--	isa	---	stigma & disclosure
<--	isa	---	uncertainty
<--	may effect	---	wsbc identity role

This code is present in 119 segment(s).

Neighbor - one living or located near another

Links

---	may effect	-->	expectations of others
---	isa	-->	wsbc identity role

This code is present in 4 segment(s).

ongoing symptoms - not described in detail.

Links

---	causes	-->	emotion work
<--	impacts	-->	identity work
---	causes	-->	negative meaning
---	isa	-->	sick role

This code is present in 21 segment(s).

patient compliance - A term used in medical settings to describe a patient's adherence to doctor's instructions. Difficult to address due to issues with racism.

Links

---	is part of the	-->	emotion work
---	is part of the	-->	health care provider
---	is part of the	-->	healthcare system
---	is part of the	-->	patient role
---	may effect	-->	quality of care
---	is part of the	-->	taking control
---	is part of the	-->	well role
<--	may effect	---	urgency of life

This code is present in 19 segment(s).

patient role - A person under health care. The person may be waiting for this care or may be receiving it or may have already received it.

Links

---	isa	-->	wsbc identity role
<--	is part of the	---	loss of control
<--	is part of the	---	patient compliance
<--	isa	---	sick role

<-- isa --- well role

This code is present in 11 segment(s).

physical factor - a factor of or relating to the body

Links

<-- impacts --> thoughts
<-- isa --- body image
<-- isa --- feminine beauty

This code is present in 80 segment(s).

Positive meaning - having a good or favorable effect

Links

--- may effect --> life changing nature of bc
--- isa --> psychological factor
<-- is part of the --- altruistic pursuit
<-- causes --- cancer is a gift
<-- causes --- giving back
<-- isa --- healthy behavior
<-- is part of the --- positive reappraisal
<-- isa --- seeing life as being precious

This code is present in 139 segment(s).

positive reappraisal - Focusing on the good things that have happened or are happening, instead of the bad things. Positive appraisal is the reframing a situation to see it in a positive light.

Links

--- is part of the --> grief work
--- is part of the --> identity work
--- is part of the --> positive meaning

This code is present in 34 segment(s).

pressure to be "normal" - as things were before BC

Links

--- causes --> emotion work
--- isa --> expectations of others
--- causes --> identity work
--- is part of the --> negative meaning
<-- impacts --> sick role

This code is present in 3 segment(s).

pressure to be a hero - pressure to be strong and silent

Links

--- causes --> concealing true feelings
--- causes --> emotion work
--- isa --> expectations of others
--- causes --> identity work

This code is present in 3 segment(s).

psychological factor - of, pertaining to, dealing with, or affecting the mind, especially as a function of awareness, feeling, or motivation

Links

<-- impacts --> thoughts
<-- isa --- cancer is a gift
<-- isa --- coping mechanisms
<-- isa --- distraction
<-- may effect --- fear of recurrence
<-- isa --- giving back
<-- isa --- loss of control
<-- isa --- loss of self
<-- isa --- mindfulness
<-- isa --- negative meaning

<-- isa --- positive meaning
<-- isa --- seeing life as being precious
<-- isa --- self interestedness
<-- isa --- socialized silence
<-- isa --- uncertainty

This code is present in 132 segment(s).

quality of care - a measurement of the health care received at a doctor, dentist or other HCPs office, local emergency room or during a hospital stay, including the manners or attitude of health care providers.

Links

<-- impacts --> emotion work
--- is part of the --> healthcare system
<-- may effect --- education
<-- impacts --> healthy behavior
<-- may effect --- patient compliance
<-- may effect --- resource
<-- impacts --> social support

This code is present in 117 segment(s).

reentry stage - involves the transition into a life that is not focused on cancer and is defined as 1-3 years after diagnosis

Links

--- isa --> survivorship stage

This code is present in 12 segment(s).

resource - A resource is a source or supply from which benefit is produced.

Links

--- may effect --> quality of care
<-- isa --- emotional support
<-- isa --- social support
<-- isa --- spiritual factor
<-- isa --- support groups
<-- isa --- taking control

This code is present in 7 segment(s).

role conflict - A situation in which a person is expected and pressured to play a role to meet the expectations and comfort of others, rather than a role that the person sees as their true self.

Links

<-- impacts --> grief work
--- causes --> identity work
--- may effect --> thoughts
<-- may effect --- uncertainty

This code is present in 23 segment(s).

seeing life as being precious - A positive meaning gleaned by some WSBC.

Links

--- is part of the --> grief work
<-- impacts --> mindfulness
--- isa --> positive meaning
--- isa --> psychological factor
--- isa --> spiritual factor
--- isa --> thoughts
<-- causes --- urgency of life

This code is present in 10 segment(s).

self interestedness - a concern for one's own advantage and well-being: physical, psychological or emotional

Links

--- is part of the --> emotion work
--- may effect --> expectations of self
--- may effect --> fear and guilt related to becoming a burden to others
--- is part of the --> identity work
--- isa --> psychological factor
--- causes --> shift from caregiver to care receiver
<-- may effect --- urgency of life

This code is present in 41 segment(s).

sexual function - The constellation of mental, physical and emotional aspects of sexuality, e.g., sexual arousal, sexual desire, sexual fantasies.

Links

--- is part of the --> grief work
<-- impacts --> identity work
--- may effect --> wife or partner
--- may effect --> wsbc's womanhood
<-- may effect --- adjuvant therapy

This code is present in 13 segment(s).

shift from caregiver to care receiver - role reversal

Links

--- is part of the --> emotion work
--- is part of the --> identity work
<-- causes --- self interestedness

This code is present in 15 segment(s).

sick role - a role related to one who is affected with disease or ill health

Links

--- isa --> life changing nature of bc
--- causes --> negative meaning
--- isa --> patient role
<-- impacts --> pressure to be "normal"
--- isa --> social factor
<-- isa --- ongoing symptoms

This code is present in 129 segment(s).

social factor - Social interactions are the acts, actions, or practices of two or more people mutually oriented towards each other's selves, that is, any behavior that tries to affect or take account of each other's subjective experiences or intentions.

Links

<-- impacts --> thoughts
<-- may effect --- fear of recurrence
<-- may effect --- healthcare system
<-- isa --- sick role
<-- isa --- social support
<-- isa --- socialized silence
<-- isa --- support groups

This code is present in 70 segment(s).

social support - support provided through social interactions with family, friends, others in some circumstances, etc.

Links

<-- impacts --> emotion work
--- causes --> isolation
<-- impacts --> quality of care
--- isa --> resource
--- isa --> social factor
<-- may effect --- employer

<-- may effect --- end of treatment
<-- may effect --- financial factor
<-- may effect --- healthy behavior
<-- may effect --- loss of friendships

This code is present in 70 segment(s).

socialized silence - The perceived and real pressure from others, for WSBC to keep silent about emotional, physical or psychological residual impacts of cancer, and return to their pre-cancer identity and life.

Links

<-- impacts --> emotion work
--- isa --> emotional factor
<-- impacts --> grief work
--- isa --> psychological factor
--- isa --> social factor
<-- causes --- concealing true feelings
<-- may effect --- stigma & disclosure

This code is present in 9 segment(s).

spiritual factor - of or pertaining to the spirit or soul, as distinguished from the physical nature, not necessarily connected to religion or religiousity.

Links

--- isa --> resource
<-- impacts --> thoughts
<-- isa --- cancer is a gift
<-- isa --- seeing life as being precious
<-- may effect --- uncertainty

This code is present in 53 segment(s).

Stigma & disclosure - Issues related to disclosure of a stigmatic feature. Stigma: affected with disease or ill health an identifying mark or characteristic; specifically : a specific diagnostic sign of a disease

Links

<-- impacts --> grief work
<-- impacts --> identity work
--- isa --> negative meaning
--- may effect --> socialized silence
<-- impacts --> thoughts

This code is present in 33 segment(s).

support groups - A group of people, sometimes led by a therapist, who provide each other moral support, information, and advice on problems relating to some shared characteristic or experience

Links

<-- impacts --> emotion work
<-- impacts --> identity work
--- isa --> resource
--- isa --> social factor
<-- is part of the --- giving back

This code is present in 14 segment(s).

Survivorship Stage - a stage of survivorship. In the context of this study, related to breast cancer.

Links

--- may effect --> thoughts
<-- isa --- acute stage
<-- isa --- long-term survivorship
<-- isa --- reentry stage

This code is present in 0 segment(s).

taking control - To assume control. Taking responsibility for yourself and your actions.

Links

--- isa --> coping mechanisms
--- is part of the --> grief work
--- is part of the --> identity work
--- isa --> resource
<-- is part of the --- patient compliance

This code is present in 23 segment(s).

thoughts - the action or process of thinking : cognition, which may be articulated and non-articulated (inferred)

Links

<-- impacts --> emotional factor
<-- impacts --> acculturation
<-- impacts --> body image
<-- isa --- cancer is a gift
<-- impacts --> cultural identity
<-- may effect --- fear of recurrence
<-- impacts --> financial factor
<-- may effect --- gendered role conflict
<-- impacts --> physical factor
<-- impacts --> psychological factor
<-- may effect --- role conflict
<-- isa --- seeing life as being precious
<-- impacts --> social factor
<-- impacts --> spiritual factor
<-- impacts --> stigma & disclosure
<-- may effect --- survivorship stage
<-- may effect --- urgency of life
<-- may effect --- wsbc identity role

This code is present in 14 segment(s).

Uncertainty - The state of being uncertain; doubt; hesitancy.

Links

--- is part of the --> emotion work
--- isa --> negative meaning
--- isa --> psychological factor
--- may effect --> role conflict
--- may effect --> spiritual factor
--- may effect --> urgency of life
<-- may effect --- fear of recurrence

This code is present in 9 segment(s).

Urgency of Life - The urgency to live resulting from the fear of death.

Links

--- isa --> emotional factor
--- is part of the --> grief work
--- is part of the --> identity work
--- may effect --> mindfulness
--- may effect --> patient compliance
--- causes --> seeing life as being precious
--- may effect --> self interestedness
--- may effect --> thoughts
<-- causes --- fear of recurrence
<-- may effect --- uncertainty

This code is present in 5 segment(s).

well role - a role related to one who is free or recovered from infirmity or disease

Links

--- isa --> patient role

<-- is part of the --- patient compliance

This code is present in 19 segment(s).

Wife or partner - a female partner in a marriage or otherwise committed relationship

Links

--- may effect --> expectations of others
--- isa --> wsbc identity role
<-- may effect --- feminine beauty
<-- may effect --- sexual function

This code is present in 26 segment(s).

WSBC Identity role - Woman Survivor of Breast Cancer. An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition.

Links

--- may effect --> negative meaning
--- may effect --> thoughts
<-- isa --- community member
<-- isa --- employee
<-- isa --- family member
<-- isa --- friend
<-- isa --- mother
<-- isa --- neighbor
<-- isa --- patient role
<-- isa --- wife or partner

This code is present in 1 segment(s).

WSBC's womanhood - The composite of qualities thought to be appropriate to or representative of women.

Links

--- is part of the --> grief work
--- is part of the --> identity work
<-- may effect --- body image
<-- may effect --- sexual function

This code is present in 13 segment(s).

Appendix B: Coding Structure

Figure 8: Coding Structure (Emotion Work)

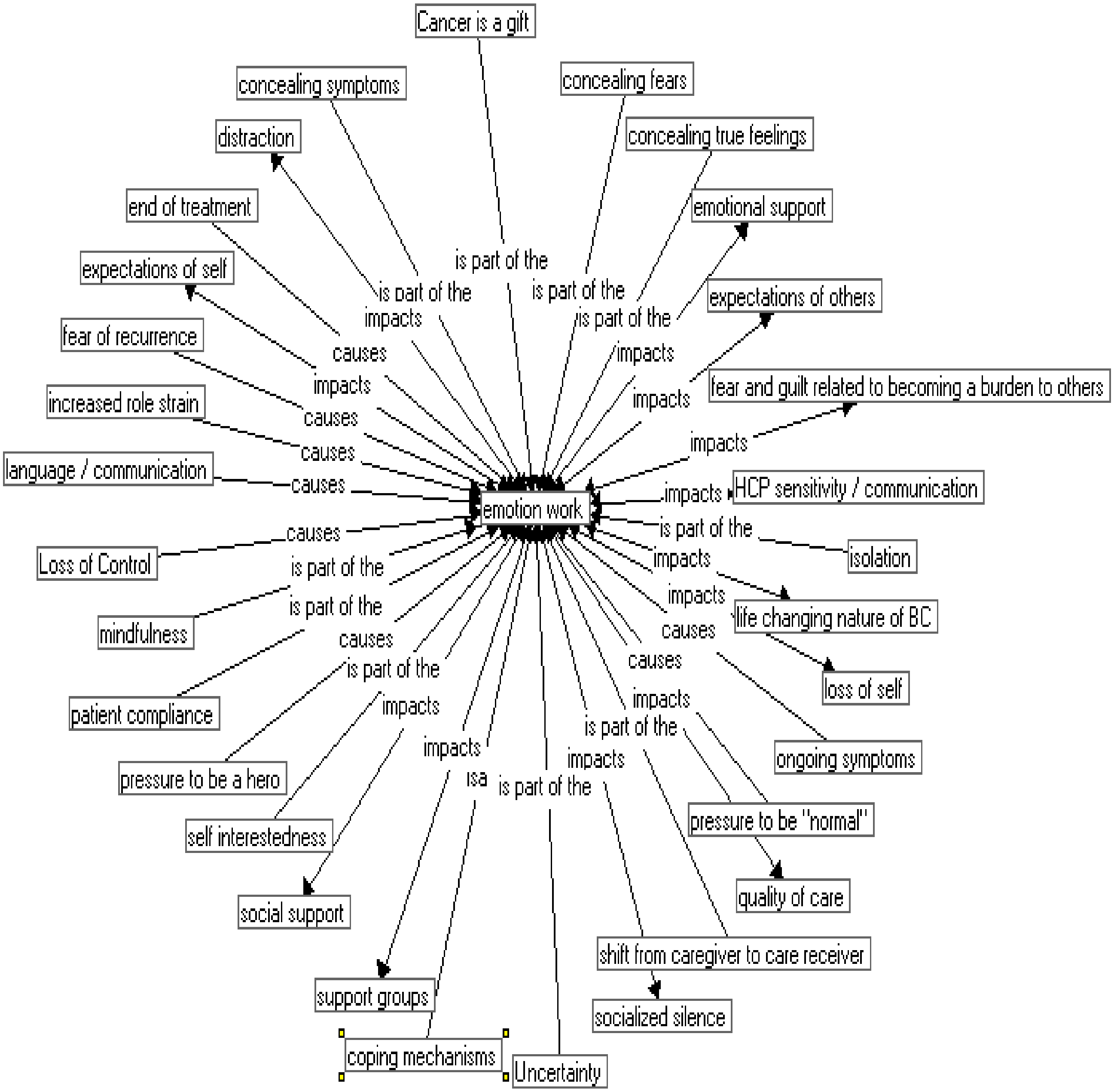


Figure 9: Coding Structure (Grief Work)

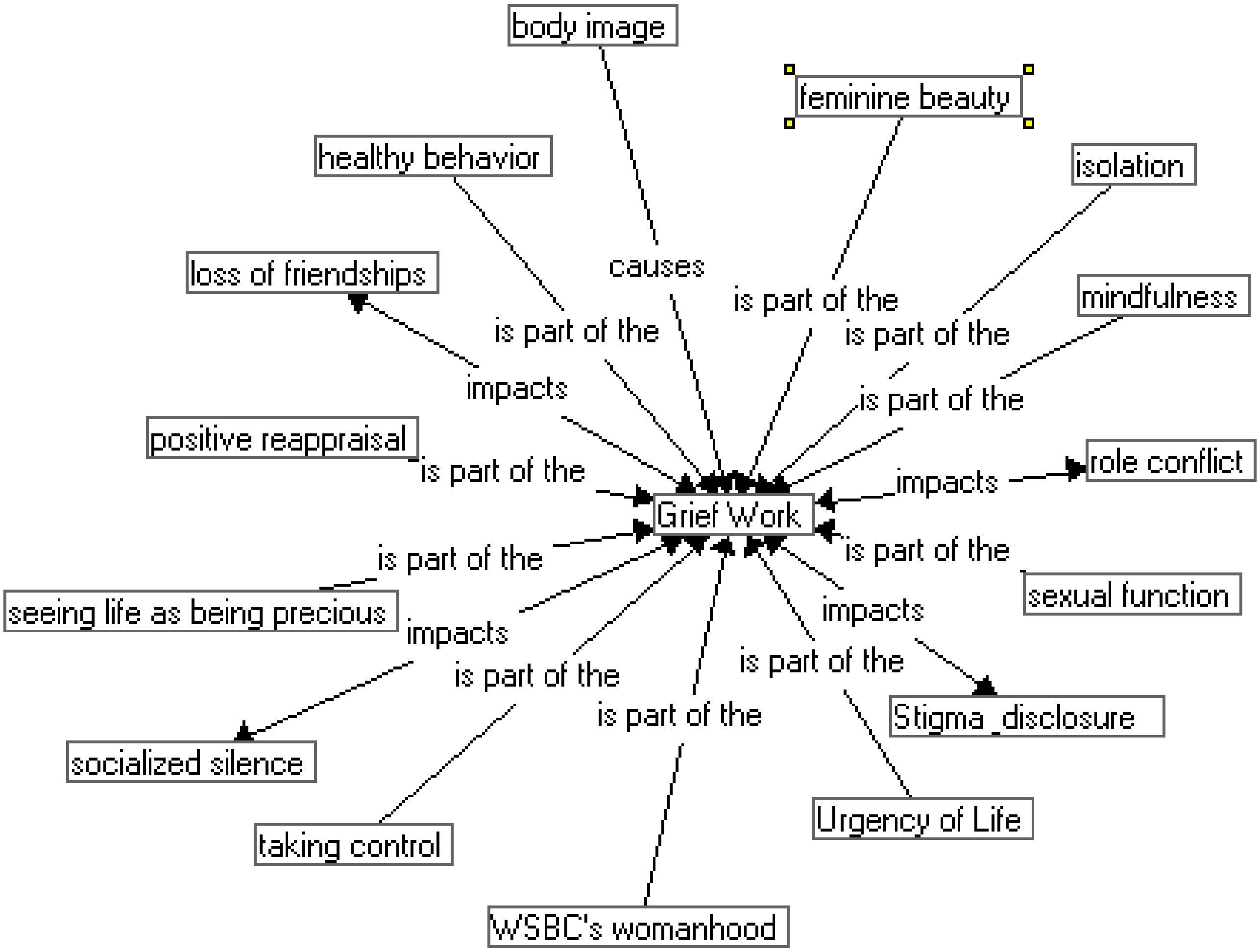
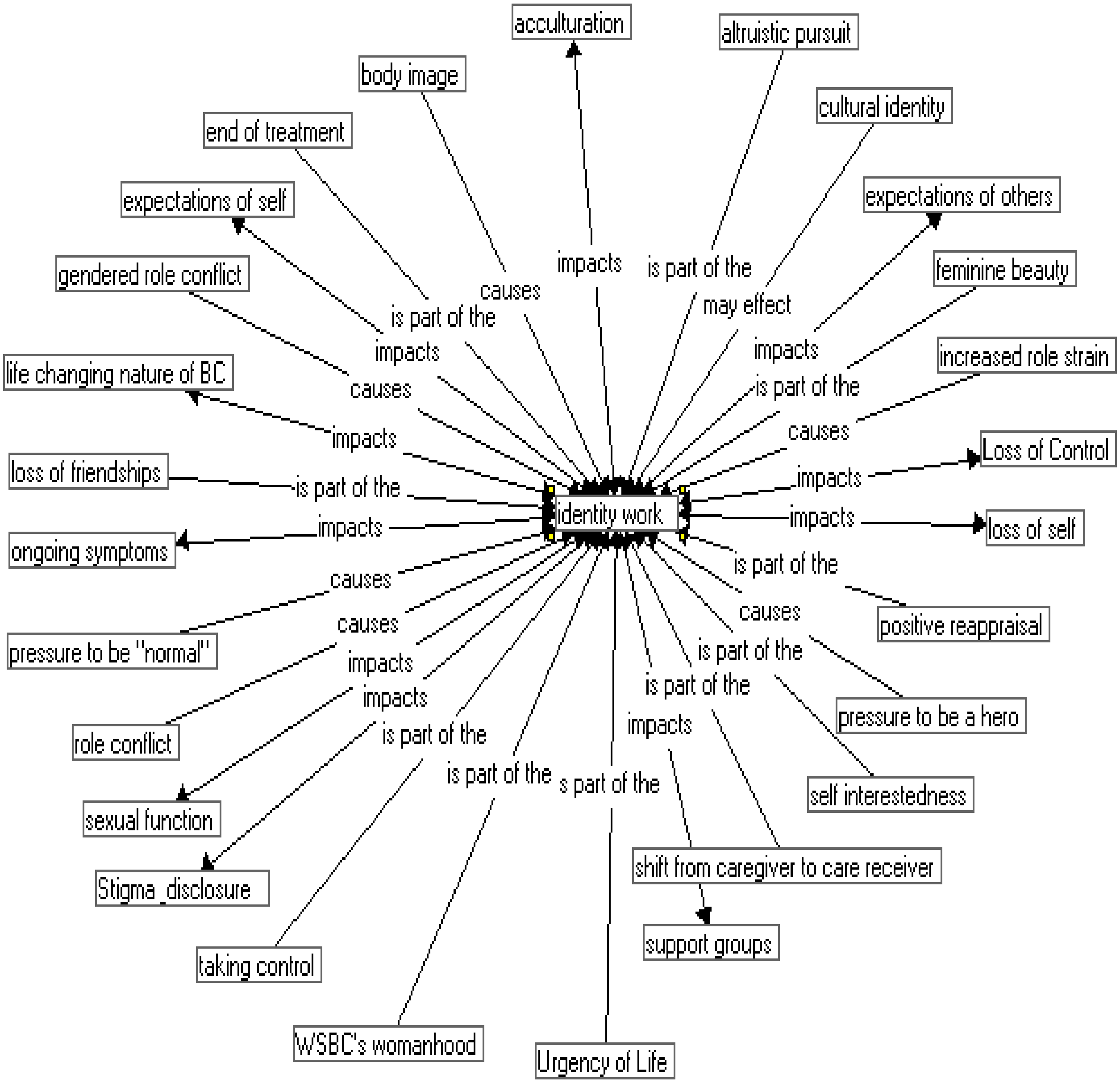


Figure 10: Coding Structure (Identity Work)



Appendix C: Syntheses of Edited Findings

Synthesized Findings 1: External / Internal Factors

Factor	Edited Findings Tied to External or Internal Factors.
Emotional	• Women talked about how having cancer had enhanced their appreciation of life and their willingness to do things that they had always wanted to do, but had put off, including helping others with BC, provided a sense of empowerment. • Some women also discussed the importance of adopting of new health behaviors and lifestyles included controlling stress levels and workload, and taking better care of themselves. • Majority of WSBC revealed persistent and troubling fears about disease recurrence sometimes triggered by physical symptoms of unknown origin • The end of treatment was associated with loss of friendships developed during treatment, emotional distress and a sense of loss for many women. Many survivors felt they were dismissed by their cancer specialists and used language of abandonment. • Survivors derive reassurance from the expertise of specialty care and surveillance and associated the emotional connection with their providers with more effective treatment. • WSBC were burdened with the responsibility for self-monitoring following treatment and worried about their inability to distinguish 'normal aging' from signs of cancer recurrence • A salient theme was the struggle to return to the life that they led before their breast cancer diagnosis, a deterministic attitude of being permanently 'changed' and a “loss of innocence”, that life would never “return to normal”, and experiencing unrelenting worries and anxiety about recurrence and the constant focus on “symptoms”. • Participants reported that even their closest confidantes misunderstood how cancer had changed their lives. The thought was especially frightening because participants sometimes feared they were becoming estranged from others, which brought a sense anxiety and loneliness. • Loneliness was part of the experience of the WSBC when they realized that others were not aware of the ongoing aspect of their breast cancer experience. • Many WSBC expressed discomfort about being called a 'cancer survivor'. • Women struggled with the pressure to resume family, work, and social responsibilities • Experienced an added burden of needing to 'be strong' for family members as they transitioned out of treatment, even though they still had physical or emotional needs. • Women's guilt about burdening their families and others with their illness contributes to distress, even if the source of burden is clearly outside of their control. • WSBC portrayed how their spouses, family members, and friends, fueled by

Factor	Edited Findings Tied to External or Internal Factors.
	popular discourse about breast cancer survivorship, believed that the cancer experience was over when, in fact, it was enduring. This resulted in feelings of helplessness when women described the unmet need to be seen and affirmed in the reality of their enduring experiences. • They felt pressure to act like a hero (conceal their fears or ongoing symptoms) and sometimes look better than they felt. • Uncertainty about the future plagues them even after the treatment is completed. • Support groups provided women with an additional resource, specifically the theme of feeling understood and encouraged by other survivors. • Although many acknowledged initial fear upon hearing the cancer diagnosis, spirituality served as a source of comfort, enhanced confidence, and lessened fears. • Women from all ethnic groups described negative feelings about their bodies after breast cancer and its treatments. Common sentiments include decreased self-worth and attractiveness, feeling deformed, inadequate, sad, embarrassed, frustrated, and/or a sense of loss. WSBC sometimes described the sense that their bodies had betrayed them and could no longer be trusted. • Sense of self and “self-distinctiveness” as a sexual creature was lost in the experiences of diminished sexual arousal, dry vagina, and loss of breasts. • The deviation in appearance (loss of hair due to chemotherapy) was a significant source for feelings of “markedness.” • WSBC experienced feelings of vulnerability due to not having one or both breasts, especially when they needed to put on a swimsuit or wear a nightgown, when dressing or undressing in front of their partners, or when looking at the mirror (especially for the first time), making love, and hugging people. • Among most survivors, the current neighborhood did not impact stress levels or the ability to cope with cancer. • Difficulty remembering things and concentrating were reported by 60% to 80% of participants at 3 months and persisted throughout the 1st year. Changes in cognitive ability were distressful. • Psychological concerns, such as the fear of recurrence, were identified as a cause of sleeping problems. • Weight gain was reported to be very distressing. • The most frequently reported psychological concern was fear of recurrence, which persisted throughout the 1st year and resulted in heightened tension about follow-up calls from physicians, time waiting for test results, and their responses to physicians' questions during office visits. • Anxiety was common during the 1st year, whereas changes in mood and feeling sad or blue diminished over time. • WSBC experienced the emotional impact of facing their denial regarding negative marital issues or relationships and realizing that their illness was going to upset the already precarious balance of the relationship.

Factor	Edited Findings Tied to External or Internal Factors.
	• WSBC were surprised that they continued experiencing pain, fatigue, impaired limb movement, and poor memory or concentration even years after cancer treatment, which resulted in anger and disappointment. • WSBC speculated that clinicians withheld information about ongoing symptoms because they did not want to scare women. Women sometimes withheld symptom complaints because they feared that they could negatively influence or even risk the loss of relationships with their doctors. Women felt misunderstood or were accused of feigning or exaggerating their symptom experiences. • Survivors felt in “limbo” in that they had no providers within the healthcare system exclusively devoted to their unique needs and that having to repetitively transfer medical records and explain their medical history to various care providers degraded the quality of their care. • “The need to become more individualistic” marked a shift of perspective from thinking about others to thinking about oneself a necessary coping strategy for managing the life-changing aspects of breast cancer treatments, side effects, interruptions to daily routines, strains on relationships, and existential fears. Such attributes also conflict with the nurturing, other-focused traits typically associated with being female, and many women characterize them as desirable as well as selfish and guilt-inducing. • Ethnic minority women discussed the salience of support from immediate and extended family to emotional well-being and treatment adherence. • The African American cultural tradition of surviving severe obstacles served as testimony of having the strength to also fight cancer. • Concerns about the illness affecting their roles as caregivers and the impact on their families were mentioned by African American, Asian American and Latina women. • African American women expressed fears related to unfamiliarity with breast cancer, inability to attend to one's own health, and racism and insensitivity within the health care system that resulted in poor quality care and insurance coverage, and loss of trust, some of which can be traced to continuing fear and suspicion from the Tuskegee case. • Interactions with HCPs led African American WSBC to believe that it was safer to rely on themselves for care. • African American WSBC felt that they would rather live without men if it meant sacrificing themselves. If the men could not cope with their breast cancer diagnosis or change in appearance after surgery, the women preferred that those men move on. • Asian Americans and Latinas discussed how keeping busy with activities distracted them from feeling emotionally overwhelmed. • Along with fears about changes in body image and scarring, some Asian American and Latina women discussed worries about the effects chemotherapy and surgery. • Asian Americans and Caucasians believed that one's attitude and motivation was more important than educational level per se in receiving quality care.

Factor	Edited Findings Tied to External or Internal Factors.
	• Latinas whose spouses had left them after the cancer diagnoses and treatments expressed lack of interest in getting involved in another relationship to avoid rejection and betrayal. • Latina WSBC in the re-entry stage reported new attitudes toward life (e.g., enjoying life more), others (e.g., expand their social network), self-care (e.g., valuing prevention more), and themselves (e.g., increased self-esteem). • Feeling that their partners loved them and accepted their new body image (e.g., breast removed) encouraged Latina survivors to also accept their bodies, increasing their feelings of self-confidence. • For several Caucasian WSBC, apprehensions about incapacitation and loss of autonomy were greater than fears about death. • Caucasian WSBC experienced both “active coping” (expressing a positive attitude) and “passive acceptance/resignation” (feeling they did not have much control over the disease nor the treatment).
Financial	• Women from all ethnic groups felt that financial status was an important determinant in the quality of care received • Economic barriers were particularly salient for African American and Latina survivors. Economic-related discrimination was a major concern for many of the African Americans. • Over half of the Latinas and some of the monolingual Asian Americans found it difficult to follow and meet requirements for treatment-related financial assistance. • Insurance status was another factor resulting in discriminatory treatment mentioned by Caucasians and Latinas. For example, a survivor described suffering in relation to not being able to afford procedures and prescriptions. • Caucasian survivors described difficulties in enrollment (e.g. denial of coverage) or in receiving payments from an 'accelerated life insurance' plan (i.e. life insurance payments for those who will die from a terminal illness within 1 year). • African Americans and some monolingual Asian Americans were also concerned with Medicare and HMO insurance limitations on hospital stay. • Most Caucasian survivors either were not working at the time of diagnosis or had stopped working due to residual pain from treatment. • Most Asians who disclosed their diagnosis in their work environment reported receiving support from employers and co-workers, while others received no support and felt pressured to leave their job. • Employment was a major concern for Latinas. Few maintained their positions. Unfortunately, some did not attend all treatment in order to avoid termination. These women worried about being unable to financially support their families, and felt that cancer had a significant effect on their employability. Having the means to pay for treatment was synonymous with a chance to survive.
Physical	• WSBC experienced a positive aspect of the cancer experience related to

Factor	Edited Findings Tied to External or Internal Factors.
	adoption of new health behaviors and lifestyle changes that were made in order to improve their general health and prevent cancer from recurring • Fears of recurrence were triggered by physical symptoms of unknown origin • Women from all groups spoke of difficulties in adjusting to physical changes from cancer. • Some women commented on the negative physical and psychological effects of breast cancer and its treatments on QOL, including decreased appetite, increased fatigue, recurring pain, loss of physical strength. • While some WSBC did not minimize their painful experiences, they reported that overall breast cancer had a positive effect on their lives. • The most prevalent physical symptom reported by women at all phases of survivorship was fatigue. Many of the participants interviewed did not anticipate the intensity or the duration of the fatigue they experienced following treatment. This resulted in anger and disappointment. • Sleep difficulties and hot flashes ranked third among physical symptoms reported by women. In some cases, difficulty sleeping was related to hot flashes. • Changes in sexuality and sexual function were commonly reported in the post treatment phase and were frequently attributed to a decrease in libido. • Weight gain was reported to be very distressing, with many women describing that they felt that it was easier to gain weight after treatment and that it was more difficult to lose weight. They also felt they were unprepared for the possibility of weight gain and would have preferred to have information in advance to help counter or prevent it. • Weight gain was particularly problematic for Latinas in affecting their body image. • Women were surprised that the symptoms they had experienced during treatment (pain, fatigue, impaired limb movement, and poor memory or concentration), never disappeared but remained part of their lives, and made them feel hypochondriacal. • Women described feeling unprepared to expect decreased sensation resulting from removal of a breast or nipple, which lessened their sexual arousal. • In general, older women (50 years and older) experienced less or no negative impact on their sex life and relationships compared to younger women. • WSBC experienced physical problems associated with screenings including discomfort during the mammogram, scars and fibroids that complicate performing self-exams. • The deviation in appearance (loss of hair due to chemotherapy, or breasts due to surgery) was a significant source for feelings of “markedness.” When a woman becomes visibly different from everyone else (considering the context of illness), she finds herself positioned as the “other,” the “strange,” and the “deviant.” However, it is not the change in physical appearance per

Factor	Edited Findings Tied to External or Internal Factors.
	se that has a meaning or shapes one's actions but the responses of others to it (including the anticipated responses). • When one's bodily presence violates the expectations of an audience, as a bald female does, it might result in the disruption of the flow of interaction and discredit one's social identity. The degree to which one's stigmatized condition interferes with social interaction plays a significant role in the ways in which one experiences the discrediting implications of his/her stigma. • Almost all Asian Americans and Latinas, and most Caucasians reported doctor recommendations of healthier diet and/or exercise to aid recovery. • Pain was mentioned most frequently by Asian Americans and Latinas as a barrier to adhering to exercise recommendations • African American, Asian American, and Latina survivors noted that self-acceptance is more difficult for younger women, as there is more emphasis on physical appearance and concern about breast reconstruction. • One contributor to fatigue for African American women may be the commitment they have to physically caring for others. • African American WSBC experienced concerns about body appearance included issues surrounding total body hair loss from chemotherapy, keloid formation at the surgical site, appearing unbalanced when clothed, and the inability to find a prosthesis that matched their skin tones. • African American WSBC expressed that “breasts could not think or make choices”, and therefore breasts did not fit their definition of being an attractive Black woman. Beauty was found not in breasts, but in a woman's mind.
Psychological	• Women talked about how having cancer had enhanced their appreciation of life and their willingness to do things that they had always wanted to do, but had put off, provided a sense of empowerment. • The end of treatment was associated with a sense of loss for many women. • WSBC experienced a sense of loss of the friendships they had developed with other breast cancer patients going through treatment, and the fact that they would no longer have that regular contact and support when treatment was over. • A sense that life will never completely return to 'normal’, and a “loss of innocence” that they would never return to a pre-cancer state. A salient theme was the struggle to return to the life that they led before their breast cancer diagnosis. • WSBC experienced an added burden of needing to 'be strong' for family members as they transitioned out of treatment, even though they still had physical or emotional needs • Uncertainty about the future plagues WSBC even after the treatment is completed • Support groups provided women with an additional resource, specifically the theme of feeling understood and encouraged by other survivors.

Factor	Edited Findings Tied to External or Internal Factors.
	• Some women commented on the negative physical and psychological effects of breast cancer and its treatments on QOL, including decreased appetite, increased fatigue, recurring pain, loss of physical strength, emotional/psychological side effects (e.g. increased irritability, depression), and memory loss. • Difficulty remembering things and concentrating were reported by 60% to 80% of participants at 3 months and persisted throughout the 1st year. Changes in cognitive ability were distressful. • The most frequently reported psychological concern was fear of recurrence, which persisted throughout the 1st year. • Anxiety was common during the 1st year, whereas changes in mood and feeling sad or blue diminished over time. • WSBC were consistently surprised when others acted as if the breast cancer experience never happened or treated the experience as “over” following the first year. • WSBC felt pressure to act like a hero (conceal their fears or ongoing symptoms) and sometimes look better than they felt. Even when it did not represent their true experiences. • Lack of preparation for lingering symptoms resulted from the fact that the women were not counseled or informed to expect symptoms to continue over time and also intensified the women's distress because it led them to question their judgment. • In addition to body-image changes, women sometimes described the sense that their bodies had betrayed them and could no longer be trusted. • WSBC experienced a lost sense of self-distinctiveness. • The sense of self as a sexual creature was lost in the experiences of diminished sexual arousal, dry vagina, and loss of breasts. • Feelings of helplessness arose when women described the unmet need to be seen and affirmed in the reality of their enduring experiences. This was affected by the popular discourse about breast cancer survivorship that relegated their experiences to the past (that she had “recovered” or “survived” from a past event) even though the experience was ongoing. • Survivors usually defined survivorship in relationship to what it meant to experience cancer; these overarching attitudes often shaped their expectations for care, including seeing themselves as life-long cancer patients. • Survivors also expressed various views about life after cancer including deterministic attitudes, wanting to embrace life to the fullest and evaluating life events in terms of still being alive. • WSBC adjust their gendered understandings of themselves in regard to care in order to accommodate deeply felt imperatives to care about and for others. Gender negotiation is reflected in their ambivalence about accepting help from others; the desire to take care of themselves, instead of asking for help; and the tendency to engage in supportive relationships with other

Factor	Edited Findings Tied to External or Internal Factors.
	breast cancer survivors, who are typically thought to be the only people who can truly understand their experience.
	• Repeatedly, women describe their efforts to break from feminine norms to cope with breast cancer, becoming self-interested, assertive, and self-reliant. When successful, these efforts have the potential to promote agency and empowerment.
	• The shift of perspective from thinking about others to thinking about oneself is a necessary coping strategy for managing the life-changing aspects of breast cancer treatments, side effects, interruptions to daily routines, strains on relationships, and existential fears.
	• WSBC found themselves empowered by a new set of dispositions, and the sense of agency that accompanied them. This resulted in feelings of self-confidence, empowerment, or even a new sense of individual identity as women would often conflict with others' expectations. When this occurs, the individuation that was at one time a viable coping mechanism becomes tainted with feelings of selfishness.
	• When coping with breast cancer, WSBC evaluate, negotiate, resist, and renew their identities.
	• WSBC experienced a conflict between their needs and expectations for themselves and the internalized scripts that define women in terms of their ability to yield to the needs and expectations of others.
	• Women's engagement in formal and informal support to other breast cancer survivors stems from an attempt to gain understanding, and to balance the self-interestedness that becomes necessary when responding to their illness.
	• Some Caucasians and African Americans reported that family members' own coping difficulties impaired the provision of needed support.
	• Mental stability was frequently described as a spiritual awakening or reconnection by women in the African American groups.
	• The more acculturated Asian American women cited avoidance of isolation, avoidance of dwelling on the illness, and having a positive attitude. In general, the Asian Americans noted the importance of accepting the illness.
	• The adverse effect of stress on health and the importance of a positive attitude were taught to the Caucasians and Asian Americans as children.
	• African American, Asian American, and Latina survivors noted that self-acceptance is more difficult for younger women, as there is more emphasis on physical appearance and concern about breast reconstruction.
	• For Latina WSBC in the acute stage of survival, markers of psychological well-being included accepting the diagnosis, having a chance for a cure, and “feeling confident.”
	• The psychological impact of the diagnosis was greatest among Latina WSBC in the acute stage, while the psychological impact of treatment was greatest among Latina in the reentry stage.
	• Long-term Latina survivors perceived psychological well-being as a change from a previous state (e.g., feeling self-assured, safe, and free of pressures

Factor	Edited Findings Tied to External or Internal Factors.
	and worries). They reported new attitudes toward cancer (e.g., not resenting the diagnosis anymore), life (e.g., living according to their values), self (e.g., increased self-value), their bodies (e.g., accepting body image), family (e.g., valuing family more), spirituality/religion (e.g., feeling closer to God), and others. • For African American WSBC a negative response to the breast cancer diagnosis becomes a positive story of survivorship. • Awareness of personal strengths embedded in an identity as an African American woman, including applying lessons learned from facing previous negative life events. • For Caucasian WSBC the presence of a life-threatening illness and the associated vulnerability brought life more clearly into focus. Illness motivated introspection, and they identified the need for existential or spiritual anchors in the philosophical, spiritual, and cognitive realms. • African American WSBC identified avoiding negative people was a way of coping with breast cancer. Participants felt strongly that negative people did not make them feel positive about their situation and tended only to bring down their spirits. Participants described negative people as individuals who made inappropriate or negative comments regarding their condition. • Having a will to live for self and others served as a driving force for several of the African American WSBC. Women who had families, especially young children, reported that they needed to live for their children and family members. • African American WSBC reported that memorized Bible verses and prayer were ways to cope with the stress of going to surgery. • African American WSBC described a process of survivorship that takes time. It involves a reflective assessment of the diagnosis, treatment, body changes, and struggles deep within the soul that ultimately leads to renewed life. In other words, these survivors have emerged on the other side of cancer, and things look different than they did before the cancer and treatment.
Social	• WSBC experienced an altruistic sense of wanting to 'give back' or help others, out of a sense of gratitude for the help and support they had received during their treatment, providing a sense of empowerment. • Women struggled with the pressure to resume family, work, and social responsibilities. • Receiving support from others, whether it be family, friends, and/or in the context of a support group, was emphasized as key in the recovery and coping process. • Support groups provided women with an additional resource, specifically the theme of feeling understood and encouraged by other survivors. In addition, support groups provided a means of obtaining valuable information regarding treatment and recovery. • Women's engagement in formal and informal support to other breast cancer survivors stems from an attempt to gain understanding, and to balance the

Factor	Edited Findings Tied to External or Internal Factors.
	self-interestedness that becomes necessary when responding to their illness. • Participants reported that even their closest confidantes misunderstood how cancer had changed their lives. The thought was especially frightening because participants sometimes feared they were becoming estranged from others, which brought a sense anxiety and loneliness. • Social circles of influence inspired survivors' healthcare diligence. • Reservations about dating were discussed by single African American, Latina and Asian American survivors. • Latina WSBC in the reentry stage reported that support from family members, professionals (e.g., doctors, social workers), peers, and spiritual sources was very important to them. Participants who reported lacking social support were less confident about the choices they made about treatment and were less optimistic about their future than those who perceived adequate support. • African American WSBC reported receiving personalized support from a social network including the church pastor. • African American and Caucasian WSBC reported that being able to maintain social roles made them feel needed. • WSBC in African-American communities avoid discussing breast cancer and that this social taboo can inhibit diagnosis, treatment, and support for survivors. • African Americans have been part of and separate from the American society for decades. This separation has led to both strengths and distrust. Understanding the historical meanings of “socialized silence” about cancer in the African American is important.
Spiritual	• WSBC adopted new health behaviors, such as exercise, quitting smoking, eating a healthier diet, controlling stress, engaging in spiritual practices, and for some, use of complimentary or alternative medicines. • Family support, spirituality, and support groups were all very important to the women's recovery and coping. • Spirituality was highlighted as a fundamental component of the healing process. Although many acknowledged initial fear upon hearing the cancer diagnosis, spirituality served as a source of comfort, enhanced confidence, and lessened fears. In particular, survivors noted that their faith and God's direction over the doctors healed them. • The shift of perspective from thinking about others to thinking about oneself, “the need to become more individualistic”, is a necessary coping strategy for managing the life-changing aspects of breast cancer treatments, side effects, interruptions to daily routines, strains on relationships, and existential fears. • African American, Asian American, and Latina BCS emphasized the significance of spirituality and prayer on their recovery. These women considered God an important source of support. • A number of Asian American and Latina survivors felt that the outcome of

Factor	Edited Findings Tied to External or Internal Factors.
	the illness and their fate was ultimately controlled by God, regardless of their actions. • Religious beliefs that influence health practices were deemed essential to handling an illness by African Americans, Latinas and less acculturated Asian American survivors. • African American WSBC were able to face difficulties with strength drawn from faith and the culture, affirming existing beliefs in God's guidance, finding direction and strength by focusing on a concept of God's will for her life, and developing a sense of breast cancer survival as a consequence of God's intervention as a woman living out a destiny ordained by God. • Caucasian WSBC reported that the presence of a life-threatening illness and the associated vulnerability brought life more clearly into focus, that illness motivated introspection, and the need for existential or spiritual anchors in the philosophical, spiritual, and cognitive realms. They expressed the need for a form of spiritual connection, a desire to find some direction in life and to find meaning in the illness. • African American WSBC reported that their relationships with God grew stronger because of having breast cancer. • African American WSBC spoke of the importance of spirituality and personal growth as a result of experiencing breast cancer. They saw faith as an important part of African American culture as a way to rise above and deal with adversity.

Synthesized Findings 2: Developed Roles

Identity Role	Edited Findings Tied to Developed Roles.
Friend	• Loss of friendships that were previously developed with other WSBC when undergoing treatment. • Importance of support from friends especially during re-entry stage. • Positive impact to psychological state from emotional support of friends. • Instrumental support through changes in living arrangements. • Friends as source of information and interpretation of same, for cancer experiences. • Negative friends had negative impact. • Lack of understanding of on-going nature of BC experience and lingering symptoms, leads to loneliness. • Close friends not understanding the life-changing dynamic of BC experience leads to anxiety and loneliness. • Pressure to be “silent” and conceal true feelings (act like a hero) with friends. • Friends helped inspire healthcare diligence (diets, exercise, schedule, etc.). • Gendered role conflict as a care-giver vs asking for help from friends, and guilt resulting from their burdening others even when source of burden is out of their control. • Shift from “other-centered” to “self-interestedness” as a necessary coping strategy to strains on relationships. • Impact of feminine beauty after BC on male relationships resulted in internal conflicts. • African American WSBC expanded the definition of “family” to include friends who served as care-givers, supporting them in living at home and other supportive living arrangements. • History of the BC experience in friends of African American BCS lessened the “surprise” at diagnosis. • Concerns about dating by minority BCS.
Mother	• WSBC were challenged to adjust to role reversal from care-giver to care-receiver. • Resulting limitations related to childcare were extremely distressing. • Gendered role conflict as a nurturing care-giver who is “other-centered” vs. asking for help from others, results in induced guilt. • Asian American and Latina BCS experienced significant pressure to maintain “typical functioning” as a woman / mother during and after treatment.
Wife/Partner	• Negative marital issues / relationships were further weakened by illness. • Felt pressure to be “silent” … act like a hero, concealing their feelings, fears, etc.

Patient	• Physical effects of surgery to the breasts (impact to body image) and adjuvant treatment were unexpected and impacted sexual function, (lack of nipple sensation, vaginal dryness, loss of breasts), resulting in feeling of vulneraqbility in front of spouse/partner.. • Lack of understanding by spouse / partner of the ongoing (enduring) nature of the BC experience was disturbing. • Gendered role conflict as a nurturing care-giver who is “other-centered” vs. asking for help from others, results in induced guilt. • Asian American and Latina BCS felt significant pressure to assume their roles as a woman / wife during and after treatment. • Latina BCS were disproportionately abandoned by spouses / partners after diagnosis / treatment. • Love and acceptance of their altered body image, by spouse / partner was important to their self-acceptance of Latinas. • Caucasian BCS expressed concern and disappointment in lack of support by significant others, and sought to hide their fears and emotions to avoid negative reactions. • African American BCS expressed an increased sense of purpose and will to live for themselves and their family members. • African American BCS also struggled with the impact of their altered body image upon their relationships with men, now and in the future. Male support was seen as an important and desired aspect of surviving BC. • WSBC experienced a burden of worry and lack of control over the potential for recurrence. • Some developed a sense of altruism out of gratitude for treatment support. • Positive aspect of cancer experience due to health improvement resulting from lifestyle changes. • WSBC support to other BCS arising from an attempt to gain understanding and to balance self-interestedness. • Persistent fears of recurrence, often triggered by physical symptoms of unknown origin and uncertainty about the future, and loss of control over their bodies, at times related to follow-up calls from HCPs and time waiting for test results. • Emotional distress, ambivalence and sense of loss following completion of treatment, including chemotherapy and radiation. • Shift in responsibility to self-monitoring after treatment and potential to miss signs of recurrence, adds to the need to become more individualistic, thrusting them into the HC system to care for themselves. • Loss of significant support after end of treatment phase. • Permanent label as “cancer survivor” can be uncomfortable, resulting in a “loss of innocence” … never being able to return to a pre-cancer state, comparing “pre” vs. “post” cancer. • Survivorship can lead to positive deterministic attitudes, wanting to embrace life and living to the fullest. • Need to be strong for others as they transitioned out of treatment, even

	though still having physical and emotional needs and the resultant guilt about burdening their families, even though the source of the burden is clearly out of their control. • Lack of preparation for transition from treatment to survivorship, including the ongoing symptoms, such as pain, fatigue, impaired limb movement, memory loss, lack of concentration and other cognitive issues. • Need for emotional attachment to HCP for more effective treatment. • Social identity of "survivorship" included the assumption that the BCS's experience was a "past event", even though the experience was ongoing. • Identity management as an outcome of the BC experience, where WSBC, when coping with BC, evaluate, negotiate, resist and renew their identities. • Asian Americans expressed the importance of support from family members for emotional well-being, treatment adherence and overall recovery. • Asian Americans, Latinas and African American BCS also felt a disproportionate need to continue in their roles as caregivers, in spite of their illness. • Asian Americans, Latinas and African American BCS also experienced barriers and/or discriminatory treatment in accessing care. • African American, Latina and less acculturated Asian American BCS emphasized the importance of religious beliefs in handling an illness. • African American BCS especially spoke of the strength gained from their relationship with God, and the desire to be treated by a HCP that expressed a belief in God. • African American BCS spoke about the social taboo regarding speaking of breast cancer in African American communities. • The financial and physical effects, including workplace disruption and body image adjustments were of specific concern to Latinas. • Caucasian BCS sought an adaptive position that grew from the initial shock at diagnosis, to a growing realization of the implications of the illness, through a shift to passive acceptance and/or resignation.
Neighbor	• There was a general sense of boundaries established between the WSBC and their neighbors across cultures. • There was a definite preference that the diagnosis and ongoing treatment be kept "within the family". • Involvement with neighbors tended to result in stress and discomfort on the part of the WSBC.
Community Member	• Engagement with the larger community, specifically BC support groups, provided both a means of support to the WSBC and an outlet for fulfilling the desire to "give back" to other WSBC. For some, this provided a balance to the self-interestedness that became necessary in response to their illness. • African American WSBC especially, realized support from within their wider community of African Americans, which was not limited to their neighborhoods, but was expanded to other church and social networks they participated in. • Maintaining the roles established within this social groups was important to

	these WSBC. • African American WSBC also experienced the unique impact of “socialized silence” resulting from the historical context of their culture. • Due to the separateness of African Americans within the larger American society, both strengths, in the form of mutual support and common experience, and vulnerabilities, in the form of silence and distrust of the healthcare system, are evident. • African American WSBC also appear to suffer disproportionately from the silence related to the social taboos placed within their community to discussing breast cancer, which can inhibit diagnosis, treatment and support for survivors.
Employee	• The response to WSBC from employers was uneven and varied both across and within cultures. • A common element was the perceived pressure to act like a hero by concealing their fears or ongoing symptoms in work situations. • The physical effects of treatment had varying effects on the WSBC as employees, in some cases leading to their stopping working due to residual pain, or changing jobs to avoid uncomfortable situations. • Latinas experienced a disproportionate impact to their positions, with many losing their jobs due to excessive absence or changes in work performance due to treatment or ongoing symptoms.
Family Member	• WSBC struggled with the pressure to resume family responsibilities. • Limitations were particularly distressing when they impacted child care. • WSBC experienced the burden to “be strong”, and act like a “hero” (concealing their fears or ongoing symptoms) for family members as they transitioned out of treatment, even though still having physical and emotional needs. • Family support was very important to recovery and coping, and helped survivors adjust health behaviors for the better. • WSBC recalled that cancer was not discussed openly in the family during childhood. • WSBC voiced concerns in relating to family members after treatment. • Lack of understanding by family members of the on-going nature of the BC experience, and that it had “changed their lives” led to loneliness and anxiety. • WSBC expressed need to relate the importance of BC screening to family members. • WSBC experienced guilt related to conflicts between their deeply felt gendered role as nurturing, other-focused caregiver vs. their need to focus on themselves and become a care receiver. • Seeing themselves as a burden to their families was a common theme that resulted in further guilt, even though they had no control over the source of the burden. • The aspect of family as both a positive and negative aspect was a persistent theme amongst ethnic minority WSBC.

- Family was at times a primary source of support and care throughout the stages of survival.
- At other times, family was seen as a source of strain related to reluctance to disclose the illness and become a burden on the family.
- Caucasian WSBC reported that family members were challenged in adjusting to their new role as caregivers.
- Caucasian WSBC also tended to withhold their fears and/or intense emotions (emotional avoidance) due to concerns over reactions from family members.
- African American and Latina WSBC expressed fears that family members would develop breast cancer.
- African American and Latina BCS reported new attitudes (positive re-appraisement) towards cancer, life, self, their bodies, family and spirituality.
- The support of the family was especially evident in the reports of African American WSBC, providing both tangible (informational, assistance to live at home and maintain social roles, etc.), and intangible (emotional, encouragement, etc.) support.

Synthesized Findings 3: Emotion Management

Synthesis of Edited Findings: Emotion Management	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
Self-Interestedness	Participants across stages shared similar perceptions about some of the markers of psychological well-being (PWB), such as feeling good, feeling self-assured, and not feeling depressed.
	Women reported new attitudes toward life (e.g., enjoying life more), others (e.g., expand their social network), self-care (e.g., valuing prevention more), and themselves (e.g., increased self-esteem).
	Feeling that their partners loved them and accepted their new body image (e.g., breast removed) encouraged survivors to also accept their bodies, increasing their feelings of self-confidence.
	They reported new attitudes toward cancer (e.g., not resenting the diagnosis anymore), life (e.g., living according to their values), self (e.g., increased self-value), their bodies (e.g., accepting body image), family (e.g., valuing family more), spirituality/religion (e.g., feeling closer to God), and others.
	As a type of emotional support, encouraging words are intended to reassure or to encourage positive self-evaluation
	Women described additional encounters in which health care providers exhibited behaviors that contributed to distrust. These encounters included being talked about as if the patient were not present and a feeling that the physician did not want to touch the patient because she was African American. These kinds of interactions led these women to believe that it was safer to rely on themselves for care.
	Even when focusing on their individual needs, taking care of themselves, or receiving care from others, they adjust their gendered understandings of themselves in regard to care in order to accommodate deeply felt imperatives to care about and for others.
	"the need to become more individualistic." This shift of perspective from thinking about others to thinking about oneself is a necessary coping strategy for managing the life-changing aspects of breast cancer treatments, side effects, interruptions to daily routines, strains on relationships, and existential fears
	Feelings of self-confidence, empowerment, or even a new sense of individual identity as women would often conflict with others' expectations.
	The goal of self-reliance often contains the desire to shield others from the burden of caring.
	If gender expectations that stress sacrifice, empathy, and emotional sensitivity sit squarely within a respondent's repertoire then the self-interestedness necessary to cope with breast cancer would undoubtedly conflict with it.
	the non-feminine qualities of assertiveness, self-reliance and deliberate living were echoed across the interviews when breast cancer was the motivating force for women to put themselves first and to take action to keep their needs in focus. While this action was empowering to some women some of the time, it also caused tension in their lives and ambivalence about their identities as women.

Synthesis of Edited Findings: Emotion Management	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
Synthesized finding	*Most of the women sensed the need to think about, care about and focus on themselves more. The process and work of going through and dealing with something as serious as breast cancer created a sense of strength and urgency of life and a sense of being more self-focused and increased non-feminine qualities that the women saw as positive while it caused strained or broken relationships with others in their lives. The WSBC talked about life changes such as living in the moment, increased or new spirituality and pursuing long time dreams. Some WSBC felt accepted and loved by their spouses/partners in spite of the physical changes while others reported that these changes created an issue. Latinas were particularly effected since their husbands/partners associated a loss of machismo due to the WSBC changed body. Some Latina WSBC indicated that their husbands ignored or left them due to this issue. There were mixed feelings about Health Care Providers (HCP) but African Americans felt mistrust and mistreatment in their interactions with HCPs: HCPs talked about them as if they were not there and did not want to touch them. The African American women felt it best that they take care of themselves and some abandoned treatment.*
Fear & guilt related to being a burden to others	family members' challenges adjusting to new roles of being caregivers and her difficulty in reversing roles with her family
	A number of Chinese survivors reported that they performed daily chores themselves even during treatments, rather than receiving help from their families
	Concerns about the illness affecting their roles as caregivers and the impact on their families were mentioned by African American, Asian American and Latina women
	An Asian American survivor expressed feeling hesitant about dating because of uncertainty about cancer recurrence and not wishing to be a burden to someone
	When faced with other survivors, they could silence or chasten themselves for thoughts they characterized as selfish or for an insufficiency of “fighting spirit.”
	Even when focusing on their individual needs, taking care of themselves, or receiving care from others, they adjust their gendered understandings of themselves in regard to care in order to accommodate deeply felt imperatives to care about and for others. Gender negotiation is reflected in their ambivalence about accepting help from others; the desire to take care of themselves, instead of asking for help
	women rely on two interrelated processes: justifying their needs to themselves and others, and being self-reliant to avoid being burdensome to others.
	Assessing the severity of their illness in terms of life or death, participants spent enormous personal resources helping others to cope with their illness with as little burden as possible. As a result, they were highly selective in the care they sought from others, men as well as women.
	In addition to self-imposed constraints, women work out power differentials within their relationships, and strains can occur when women who typically care for others need care from others. If these situations reverse "normal" gender relations so that women need care from men, added stresses can arise.
	All couples negotiate issues of power and equality within constraints from the larger society. When "normal" gender relations are reversed and women need care from men,

Synthesis of Edited Findings: Emotion Management	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
	difficulties can arise.
	Women's guilt about burdening their families and others with their illness contributes to distress, even if the source of burden is clearly outside of their control.
	a conflict between women's needs and expectations for them- selves and the internalized scripts that define women in terms of their ability to yield to the needs and expectations of others.
Synthesized Finding	*WSBC struggled with their conceptions of their roles as women and their new strength and desire to focus on themselves. The gendered role reversal with being taken care of by others, especially men, created issues for the men, as well as the WSBC. Most WSBC continued to care for others while carefully minimizing the care they took from others, especially men as part of their self imposed expectations. They chastened and/or silenced themselves when with other WSBC who they thought were selfish and who did not demonstrate a strong 'fighting spirit'. Some Chinese WSBC did not seek help from family for daily chores during treatment. African American, Asian American and Latina WSBC were worried about the impact of their illness on their families. An Asian American woman expressed concern about dating as a WSBC.*
Fear of Recurrence or On-Going Symptoms or Uncertainty	the vast majority of women also revealed persistent and troubling fears about disease, e.g. during annual exams, and heightened tension about follow-up calls from physicians, time waiting for test results, and their responses to physicians' questions during office visits
	Often, fears of recurrence were triggered by physical symptoms of unknown origin such as a skin rash.
	A significant number of women admitted having at least periods of emotional distress, and uncertainty about the future, following the completion of treatment. Sometimes, this distress or depression was directly related to fears of recurrence. Women also shared their fears about the responsibility for self-monitoring following treatment and worried about their inability to distinguish 'normal aging' from signs of cancer recurrence.
	survivors expressed similar fears regarding recurrence, death, pain, and suffering (often identified as a larger fear than dying), but focused on specific areas. The most frequently reported psychological concern was fear of recurrence.
	An Asian American survivor expressed feeling hesitant about dating because of uncertainty about cancer recurrence and not wishing to be a burden to someone
	The most prevalent physical symptom reported by women was fatigue and that their energy levels after breast cancer treatment never really returned to pre-cancer baseline. Many of the participants interviewed did not anticipate the intensity or the duration of the fatigue they experienced following treatment. In some cases, difficulty sleeping was related to hot flashes. More frequently, however, psychological concerns, such as the fear of recurrence, were identified as a cause of sleeping problems. Anger and disappointment usually came with the loss of energy.
	Loneliness and helplessness was part of her ongoing experience; it arose when they realized that others, including spouses, family members, and friends, were not aware of an ongoing aspect of their breast cancer experience (frightened about an upcoming mammogram) or memories of the experience (anniversary of diagnosis). The women

Synthesis of Edited Findings: Emotion Management	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
	validated that being alone with a reality that others did not share awakened loneliness episodically over time. This was reinforced by the popular discourse on breast cancer, which relegated it to a thing of the past.
	they felt pressure to act like a hero (conceal their fears or ongoing symptoms) and sometimes look better than they felt. Even when it did not represent their true experiences, the women reported the pressure in social situations, at work, and with friends and family.
	The women were surprised that they continued experiencing pain, fatigue, impaired limb movement, and poor memory or concentration even years after cancer treatment and remained part of their lives. The unexpected lingering of symptoms intensified distress and anxiety, which made some feel hypochondriacal, frequently calling or visiting doctors because of the need for reassurance, and leading them to question their judgment.
	Lack of preparation for lingering symptoms resulted from the fact that the women were not counseled or informed to expect symptoms to continue over time. One woman speculated that clinicians withheld information about ongoing symptoms because they did not want to scare women.
	Some women felt a “loss of innocence”; they believed that they would never return to a pre-cancer state in which they could be less somatically focused and anxious.
	Survivors usually defined survivorship in relationship to what it meant to experience cancer; these overarching attitudes often shaped their expectations for care. One survivor saw herself as a life-long cancer center patient: As a result of feeling permanently 'changed' and unrelenting worries about recurrence, many women expressed discomfort about being called a 'cancer survivor
Synthesized Finding	*Fear of recurrence was strong and could be triggered by: any physical symptom of an unknown origin, follow up visits to HCP, hearing something on TV or from others about breast cancer or about someone being diagnosed with breast cancer, as well as during annual exams, and heightened tension about follow-up calls from physicians, time waiting for test results, and their responses to physicians' questions during office visits. Besides fears of recurrence, they feared death, pain, and suffering (often identified as a larger fear than dying.) They struggled with their identity after treatment due to lack of preparation for ongoing symptoms, especially fatigue. Due to the concern of recurrence, WSBC resisted being labeled as cured, and were uncomfortable with the term ‘cancer survivor’ One women used the term patient. These fears were exacerbated when treatment ended and they were unsure of which ongoing symptoms required a trip to the HCP. The ongoing symptoms caused stress and anxiety, loneliness and helplessness. This included managing their emotions due to others sense that the BC was over. This sense of others that the BC was over was also part of the popular discourse. WSBC felt pressured to ‘act like a hero’.*
Expectations of Self	Family members' challenges adjusting to new roles of being caregivers and her difficulty in reversing roles with her family. Women rely on two interrelated processes: justifying their needs to themselves and others, and being self-reliant to avoid being burdensome to others.
	A number of Chinese survivors reported that they performed daily chores themselves even during treatments, rather than receiving help from their families

Synthesis of Edited Findings: Emotion Management	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
	The narratives reflected a strong call to be of service to others. It was important for the women to continue in this role even when undergoing treatment for breast cancer. Being able to meet their own expectations for providing hospitality to family and friends was a source of comfort. They also reflected an increased sense of urgency to carry out what the women perceived as God's will for their lives.
	One contributor to fatigue for African American women may be the commitment they have to physically caring for others. Despite the fatigue it may have caused, however, such caring was described as a positive way to cope with the treatment for breast cancer, and caring for others encouraged African American women in their recovery
	Women's responses to breast cancer can be understood as a reflection of dominant cultural scripts that define women as "natural" nurturers. As respondents speak about their experiences with breast cancer both within and outside of the medical realm, their narratives illustrate the salience of gender, particularly as it relates to compliance to others' needs and desires, rather than a prioritization of their own. For these women, changes in personal perspectives and priorities were as much about negotiating a space for themselves as women as about finding new meaning in their lives in the face of life-threatening illness. While this action was empowering to some women some of the time, it also caused tension in their lives and ambivalence about their identities as women.
Synthesized Finding	*Family members struggled with new roles of caregiving and while women struggled with the role reversal and the strain it took to manage these expectations. WSBC used two interrelated processes to manage this: justifying their needs to themselves and others, and being self-reliant to avoid being burdensome to others. WSBC felt it important to give back to others by continuing their hospitality to family and friends and to carry our God's will for their lives. African American BCS continued their tasks of caring for others in spite of the fatigue it caused, it was a positive way to deal with their illness. A strong theme of popular culture's salience of gender, especially compliance to others needs and desires with no thought of their own needs and desires emerged. This was situated within and outside of the medical realm. In spite of this, WSBC personal perspectives and priorities allowed for negotiating space for themselves and finding new meaning in their lives. While empowering, it also caused tension and identity ambivalence.*
Shift from Caregiver to Care-Receiver	Concerns about the illness affecting their roles as caregivers and the impact on their families were mentioned by all WSBC
	Women's responses to breast cancer can be understood as a reflection of dominant cultural scripts that define women as "natural" nurturers. As respondents speak about their experiences with breast cancer both within and outside of the medical realm, their narratives illustrate the salience of gender, particularly as it relates to compliance to others' needs and desires, rather than a prioritization of their own.
	such attributes also conflict with the nurturing, other-focused traits typically associated with being female, and many women characterize them as desirable as well as selfish and guilt-inducing.
	This shift of perspective from thinking about others to thinking about oneself (the need to become more individualistic) is a necessary coping strategy for managing the life-changing aspects of breast cancer treatments, side effects, interruptions to daily routines,

Synthesis of Edited Findings: Emotion Management	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
	strains on relationships, and existential fears
	When coping with breast cancer, respondents evaluate, negotiate, resist, and renew their identities. This process begins the first time a woman breaks from what has been a repeated gender performance of doing care work for others. If gender expectations that stress sacrifice, empathy, and emotional sensitivity sit squarely within a respondent's repertoire then the self-interestedness necessary to cope with breast cancer would undoubtedly conflict with it.
	In addition to self-imposed constraints, women work out power differentials within their relationships, and strains can occur when women who typically care for others need care from others. If these situations reverse "normal" gender relations so that women need care from men, added stresses can arise.
	All couples negotiate issues of power and equality within constraints from the larger society. When "normal" gender relations are reversed and women need care from men, difficulties can arise. For example, respondents had a clear understanding that caring for others required extensive mental work to anticipate and assess others' emotional and physical needs, to make appropriate decisions to meet those needs, and to provide care.
	When women care for and about others, they behave in ways that are consistent with gender role expectations and a normative feminine identity. Yet, the non-feminine qualities of assertiveness, self-reliance and deliberate living were echoed across the interviews when breast cancer was the motivating force for women to put themselves first and to take action to keep their needs in focus. For these women, changes in personal perspectives and priorities were as much about negotiating a space for themselves as women as about finding new meaning in their lives in the face of life-threatening illness. While this action was empowering to some women some of the time, it also caused tension in their lives and ambivalence about their identities as women. This was especially visible in work and family situations in which women held significantly less power within their relationships, had responsibilities that required habitually gendered performances, had less freedom to define their individual sense of self, or felt accountable for breaching others' expectations. By giving back empathy to other survivors, women with breast cancer are able to get empathy for themselves. Thus, giving back serves to reinforce and reconstruct their identities as women.
Synthesized Finding	*Women felt pressured to conform their behavior to societal gendered roles, norms and meanings caused pressure to behave in certain ways requiring habitually gendered performances. The reversal of gendered norms relating to men caring for the WSBC created problems for couples since the men did not knew the skills and amount of energy that caring for others required. Some WSBC broke the repeated gender performance of doing care work for others that caused conflict within the women and others since gender expectations of sacrifice, empathy, and emotional sensitivity conflicted with the self-interestedness necessary to cope with breast cancer. Inability to override the norms, impacted the sense of accountability for breaching others expectations. However, some WSBC reported that empathetic service to other WSBC resulted in empathy for them.*

Synthesized Findings 4: Emotion Labor (Unpaid Work)

Synthesis of Edited Findings: Emotion Labor (Unpaid Work)	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
Role Conflict, Increased Role Strain, Gendered Role Conflict	Family expectations about the woman's functioning after treatment and concerns about the illness affecting their roles as caregivers and the impact on their families were mentioned by African American, Asian Americans and Latinas. They expressed concern about disclosing their illness and burdening family.
	The narratives reflected a strong call to be of service to others. It was important for the women to continue in this role even when undergoing treatment for breast cancer. Being able to meet their own expectations for providing hospitality to family and friends was a source of comfort.
	they felt pressure to act like a hero (conceal their fears or ongoing symptoms) and sometimes look better than they felt. Even when it did not represent their true experiences, the women reported the pressure in social situations, at work, and with friends and family.
	When conflict with others' expectations occurs, the individuation that was at one time a viable coping mechanism becomes tainted with feelings of selfishness or guilt.
	If gender expectations that stress sacrifice, empathy, and emotional sensitivity sit squarely within a respondent's repertoire then the self-interestedness necessary to cope with breast cancer would undoubtedly conflict with it.
	In addition to self-imposed constraints, women work out power differentials within their relationships, and strains can occur when women who typically care for others need care from others. If these situations reverse "normal" gender relations so that women need care from men, added stresses can arise.
	All couples negotiate issues of power and equality within constraints from the larger society. When "normal" gender relations are reversed and women need care from men, difficulties can arise. For example, respondents had a clear understanding that caring for others required extensive mental work to anticipate and assess others' emotional and physical needs, to make appropriate decisions to meet those needs, and to provide care.
	As women are socialized into their gender identities, they are trained in empathy in order to have a greater appreciation for what others, particularly loved ones, are experiencing. This helps them to better understand another person's situation, perspective, and problems, i.e., to be better caregivers. It is not surprising then, that women with breast cancer seek empathy from other women (with breast cancer). As women, they are supposed to be empathetic and self-sacrificing, but to cope with breast cancer they need to break with these gender norms to focus on their own needs. By giving back empathy to other survivors, women with breast cancer are able to get empathy for themselves. Thus, giving back serves to reinforce and reconstruct their identities as women.
	Women "give back" to a community of women with breast cancer to build ties with the only people who, they believe, can truly understand their experience, women who have "been through it." In the search for empathy, women sought understanding from other women, thereby reinforcing the gendered dimension of social interaction in everyday relationships as well as within the context of breast cancer itself. These relationships enabled women with breast cancer to access informational, instrumental, and emotional

Synthesis of Edited Findings: Emotion Labor (Unpaid Work)	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
	support that was not readily available to them in other settings.
Synthesized Finding	*The pressure of others expectations for WSBC to return to 'normal' challenged the WSBC to return to roles and tasks that they were not able to accomplish due to the physical, emotional and psychological stress of living with and possibly dying of a life threatening illness. By the same token, women struggled with retaining their womanhood both in the physical body and in the emotional sense in that women are socialized to care and give to others. WSBC felt pressure from others and from within to function in the way that they thought was how they should function to maintain their status as a good wife/partner; mother; family member; friend and neighbor.*
HCP sensitivity / communication or language / communication or patient compliance	Acculturated Asian American survivors also felt that a positive attitude, educating oneself about the illness, and taking medication were beneficial to recovery, while the less acculturated Asian Americans indicated that while they participated in the decision-making, they depended on their doctors for the final treatment decision.
	The majority of the African American survivors described negative relationships, such as doctors discounting their concerns, insensitivity, and that they really did not care about them and noted that they were treated disrespectfully for asking questions. Health care providers exhibited behaviors that contributed to distrust. These encounters included being talked about as if the patient were not present and a feeling that the physician did not want to touch the patient because she was African American. These kinds of interactions led these women to believe that it was safer to rely on themselves for care
	A number of the African American, Asian American, and Latina BCS experienced barriers and/or discriminatory treatment in accessing care, lack of doctor sensitivity in listening to their concerns or in relaying diagnosis, which led to worries about trust and disclosure of information.
	The women noted that the quality of care received is based upon assumptions that others make about education level. In particular, Latinas believed that medical staff made assumptions based on inability to speak English and manner of dress, and Asian American survivors felt that medical staff gave more information to those who were more educated about the disease.
	At the end of treatment, unexpectedly, physicians no longer provided the vigilant oversight and clinical attention (which characterized the time of acute treatment) and instead could seem annoyed that the women had questions and concerns. They also felt dismissed by cancer specialists at the time that transfer of care takes place.
Synthesized Finding	*Overall African American, Asian American and Latina WSBC found many issues with HCP care. They all experienced barriers and/or discriminatory treatment in accessing care, lack of doctor sensitivity in listening to their concerns or in relaying diagnosis, which led to worries about trust and disclosure of information. Asian Americans and Latinas pointed to language barriers, education level and dress as impacting the HCP's assessment about a person's. More acculturated Asian Americans felt knowledge about the illness and medication positively impacted the HCP's impression of them. Therefore, they felt more control over their illness and thereby were able to navigate the barriers that impacted less acculturated WCBC. Institutional racism had particular meanings for African Americans. The majority of the African American survivors described negative*

Synthesis of Edited Findings: Emotion Labor (Unpaid Work)	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
	relationships; such as doctors discounting their concerns, insensitivity, and that they really did not care about them and noted that they were treated disrespectfully for asking questions. Health care providers exhibited behaviors that contributed to distrust. These encounters included being talked about as if the patient were not present and a feeling that the physician did not want to touch the patient because she was African American. These kinds of interactions led these women to believe that it was safer to be self-reliant. This caused some African American women to discontinue treatment. Finally, following the acute level of care the WSBC were dismissed by specialists without warning or transition plans and the WSBC felt that the specialists were annoyed with any questions and concerns.
Expectations of others or pressure to be normal or a hero	Some women spoke of the added burden of needing to 'be strong' for family members as they transitioned out of treatment, even though they still had physical or emotional needs.
	Family expectations about the woman's functioning after treatment was a concern expressed by some Asian Americans and Latinas
	they felt pressure to act like a hero (conceal their fears or ongoing symptoms) and sometimes look better than they felt. Even when it did not represent their true experiences, the women reported the pressure in social situations, at work, and with friends and family.
	Feelings of self-confidence, empowerment, or even a new sense of individual identity as women would often conflict with others' expectations. When this occurs, the individuation that was at one time a viable coping mechanism becomes tainted with feelings of selfishness or guilt.
Synthesized Finding	*Many women reported pressure to be strong, to act like a hero, to go back to their former level of functioning-especially true for Latinas, and to look better than they felt in social situations, at work, and with friends and family. This occurred concurrently with new sense of self-confidence, empowerment and/or individual identity and often conflicted with others expectations, which resulted in feelings of selfishness and guilt.*
Concealing fears or symptoms or true feelings.	Some women spoke of the added burden of needing to 'be strong' for family members as they transitioned out of treatment, even though they still had physical or emotional needs.
	Family was also a source of strain for some Asian American, Armenian, and Latina women. They expressed concern about disclosing their illness, or revealing their fears or intense emotions and burdening family because they were concerned about the reactions of their spouses, children, and other family members.
	The WSBC became conscious of feeling lonely when they realized that others were not aware of an ongoing aspect of their breast cancer experience (frightened about an upcoming mammogram) or memories of the experience (anniversary of diagnosis), or when they had to withhold the truth. This meant that survivors silenced themselves, masked how they were feeling, or did not share aspects of their experience, or fully reveal themselves. Distress was compounded when women felt misunderstood or were accused of feigning or exaggerating their symptom experiences.

Synthesis of Edited Findings: Emotion Labor (Unpaid Work)	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
	They felt pressure to act like a hero (conceal their fears or ongoing symptoms) and sometimes look better than they felt. Even when it did not represent their true experiences, the women reported the pressure in social situations, at work, and with friends and family.
	Women sometimes withheld symptom complaints because they feared that they could negatively influence or even risk the loss of relationships with their doctors.
Synthesized Finding	*Families caused strain for the WSBC. The realization that others were not aware of the ongoing issues of breast cancer caused women concern about disclosing fears or telling the truth about their illness, symptoms, triggers and memories such as an upcoming mammogram or anniversary. This was especially true for Asian American and Latina WSBC did not want to burden their families and/or deal with their reactions. This led to a sense of loneliness. WSBC silenced themselves, masked their feelings and did not fully share aspects of their experience or fully reveal themselves. Distress was compounded when women felt misunderstood or were accused of feigning or exaggerating their symptom experiences. WSBC withheld symptom complaints from their HCPs so as not to negatively influence or risk the loss of their relationship.*

Synthesized Findings 5: Grief Work

Synthesis of Edited Findings: Grief Work	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
Stage 1: Acute Stage, Stigma & disclosure and Socialized Silence	family was also a source of strain for some Asian American, Armenian, and Latina women. They expressed concern about disclosing their illness and burdening family
	Most women recalled that cancer was not openly discussed in the family during their childhood. They believed that it was regarded taboo to talk about having cancer.
	Some Asian and Latina survivors believed this (that cancer was not openly discussed in the family during their childhood) was in part due to lack of knowledge about cancer, particularly in their home countries. Many preferred to keep their diagnosis within their family:
	One African American noted that she first learned of other BCS within her family while informing family members about her condition. The silence and shame regarding cancer was particularly more common in the past and in certain cultures and that this can inhibit diagnosis, treatment and support.
	Disclosure to potential partners was a major concern for some African Americans and Asian Americans
	For women in the acute stage the psychological impact of the diagnosis was greatest, many struggled with markers of PWB included accepting the diagnosis, having a chance for a cure, and "feeling confident."
	The diagnosis of cancer was perceived with shock, and as a significantly negative transitional event by these women, who responded to the diagnosis of breast cancer with fear and a sense that life would be forever changed. The women then described a growing realization of the implications of the illness.
	The importance of understanding the historical meanings of "socialized silence" in the African American community cannot be underestimated. African Americans have been part of and separate from the American society for decades. This separation has led to both strengths and distrust. Silence about cancer is an issue in the African American community
Synthesized Finding	*The first stage of grieving (Denial, Numbness, Protest, Shock & Disbelief) for the WSBC was not only experienced with shock and highly negative psychological impact, but was also marked by concerns regarding both stigma and disclosure. Some of the hesitancy to disclose their illness was rooted in a "socialized silence" that could be familial and/or cultural/ historical. This was voiced most often by African American, Asian American and/or Latina WSBC. Other reasons for hesitancy were based on a desire to shield family members from burden, or a concern for disclosing their diagnosis to potential partners. It brought on feelings of fear and shame as to the stigma of being a sick person, and the sense that life would forever be changed.*
Stage 2: Emotional factor + negative	Fears of recurrence, death pain and suffering. Other times, women communicated a sense of anguish that could arise at any time, without a specific trigger.
	The end of treatment was associated with uncertainty about the future, and a sense of loss

Synthesis of Edited Findings: Grief Work	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
meaning, or End of Treatment	of continued monitoring by and support from medical professionals for many women, and that there was no longer an action plan to ward off the cancer. This led to feelings of anxiety and abandonment.
	For many women, there was a palpable sense that life will never completely return to 'normal' .. a loss of "innocence:, and the struggle to return to the life they led before their breast cancer, where they would be less somatically focused and anxious...
	For younger women, the unknown impact of treatment on fertility is often acute,
	Women from all groups spoke of difficulties in adjusting to negative feelings about the physical changes from cancer and its treatment. Common sentiments include decreased self-worth and attractiveness, feeling deformed, inadequate, sad, embarrassed, frustrated, and/or a sense of loss.
Synthesized Finding	*The second stage of grieving for the WSBC (Anger & Disequilibrium) was filled with feelings of uncertainty, anxiety and abandonment as the WSBC transitioned beyond active treatment. WSBC experienced decreased self-worth as they faced a new "reality", one framed by physical deformities, impacts to their attractiveness and potential effects to their fertility. This all leading to feelings of inadequacy, sadness, embarrassment, frustration and an overall sense of loss.*
Stage 3: Shift from CG to GR, Womanhood, feminine beauty, pressure to be normal / hero	Once treatment was completed, many women struggled with the pressure to resume family, work, and social responsibilities-precisely at a time when the support provided by others is cut off.
	Some women spoke of the added burden of needing to 'be strong' for family members as they transitioned out of treatment, even though they still had physical or emotional needs.
	family members' challenges adjusting to new roles of being caregivers and her difficulty in reversing roles with her family
	Concerns about the illness affecting their roles as caregivers and the impact on their families were mentioned by African American, Asian American and Latina women
	After the diagnosis, these women wrestled with the ideal of feminine beauty and how that related to any possible future relationships with men.
	Women's responses to breast cancer can be understood as a reflection of dominant cultural scripts that define women as "natural" nurturers. As respondents speak about their experiences with breast cancer both within and outside of the medical realm, their narratives illustrate the salience of gender, particularly as it relates to compliance to others' needs and desires, rather than a prioritization of their own.
	many women thought of themselves as transformed and truer to themselves after they learned to break from the constraining attitudes and behaviors that were typical of them prior to their diagnosis. Essentially, what women developed was a gender consciousness.
	When coping with breast cancer, respondents evaluate, negotiate, resist, and renew their identities. This process begins the first time a woman breaks from what has been a repeated gender performance of doing care work for others. If gender expectations that stress sacrifice, empathy, and emotional sensitivity sit squarely within a respondent's repertoire then the self-interestedness necessary to cope with breast cancer would undoubtedly conflict with it.

Synthesis of Edited Findings: Grief Work	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
Synthesized Finding	*The third stage of grieving for the WSBC (Bargaining & Restitution) sees the WSBC dealing with the stress of changing roles and the pressure, at times, to be someone who they know themselves not to be. They find themselves having to negotiate competing demand and expectations, from within and without, upon their changing roles. While they see themselves as anything but normal, they are expected to be strong for others and comply with their needs and desires.*
Stage 4: Body image, role conflict / strain, sexual function, isolation, loss of control, loss of friendships	Still others experienced a sense of loss as a result of the treatment itself being withdrawn. Survivors associated this transition with anxiety. Many survivors used language of abandonment. Mostly, this was related to a feeling that there was no longer an action plan to ward off the cancer.
	As a result of feeling permanently 'changed' and unrelenting worries about recurrence (including being somatically focused), many women described a “loss of innocence” and expressed discomfort about being called a 'cancer survivor',
	Family expectations about the woman's functioning after treatment was a concern expressed by some African American, Asian Americans and Latinas. This concern was related to their expected role as caregivers.
	Women from all groups spoke of difficulties in adjusting to physical changes from cancer, including unexpected weight gain and difficulty losing it after treatment. They would have liked to receive more information about what to anticipate and how to minimize or prevent weight gain.
	Many survivors described negative feelings about their bodies (that their bodies had betrayed them and could no longer be trusted) after breast cancer and its treatments, hot flashes, sexual dysfunction, feminine beauty and challenges relating to family members, including any possible future relationships with men. Common sentiments include decreased self-worth and attractiveness, feeling deformed, inadequate, sad, embarrassed, frustrated, feelings of “markedness”, vulnerability and/or a sense of loss.
	Some participants indicated that neither their oncology specialists nor their PCPs had adequately addressed the psychological needs resulting from cancer treatments and on-going symptoms. Survivors were uneasy about raising these issues with either provider group, and in their experience few providers initiated the discussion.
	All the participants emphasized that they could become conscious of feeling “alone with the illness”, and vulnerable, which brought on a sense of anxiety, when they realized that others, including their closest confidantes misunderstood how cancer had changed their lives, and acted as if the breast cancer experience never happened or treated the experience as “over” following the first year. There were not aware of the ongoing aspect of their breast cancer experience (frightened about an upcoming mammogram) or memories of the experience (anniversary of diagnosis) and they silenced themselves and withheld that truth.
	Women sometimes withheld symptom complaints because they feared that they could negatively influence or even risk the loss of relationships with their doctors.
	Women described feeling unprepared to expect decreased sensation resulting from removal of a breast or nipple, which lessened their sexual arousal, and with the chemical

Synthesis of Edited Findings: Grief Work	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
	onset of menopause, some women experienced a decreased generalized sensation and lowered sexual desire and worried that their interest in sex would never return. Their sense of self as a sexual creature was lost due to this. The women emphasized the importance that their partners continued seeing them as sexually desirable despite their own feelings.
Synthesized Finding	*The fourth stage of Grief Work for the WSBC (Depression, disorganization & despair) is where the real work of grieving takes place. WSBC were faced with the prospect of a violated, deformed and dysfunctional body, bodies that were no longer trustworthy. This led to feelings of decreased self-worth, inadequacy, sadness, embarrassment, frustration, vulnerability and loss. The WSBC expressed feelings of loneliness as they realized that those close to them did not recognize the on-going nature of the breast cancer experience, and assumed it was over … when it was far from it.*
Stage 5: Healthy behavior, taking control, urgency of life, mindfulness, self-interestedness, Positive Reappraisal, Life as being precious, Altruistic pursuits, Giving back, Cancer is a gift	Women talked about how having cancer had enhanced their appreciation of life and their willingness to do things that they had always wanted to do, but had put off. They articulated a sense of finding the 'silver lining' or feeling 'empowered' by surviving the experience and moving to a higher state of being. Many spoke about a new ability to 'not sweat the small stuff and realizing how precious life is. Themes of enhanced agency in these narratives reflected an increased sense of urgency to carry out what the women perceived as God's will for their lives. It involves a reflective assessment of the diagnosis, treatment, body changes, and struggles deep within the soul that ultimately leads to renewed life and deterministic attitudes. In other words, these survivors have emerged on the other side of cancer, and things look different than they did before the cancer and treatment.
	Many women talked about the refusal to be burdened by worry about cancer, and feeling a sense of acceptance about their lack of control over the potential for recurrence. They reported new attitudes toward cancer (e.g., not resenting the diagnosis anymore), life (e.g., living according to their values), self (e.g., increased self-value), their bodies (e.g., accepting body image), family (e.g., valuing family more), spirituality/religion (e.g., feeling closer to God), and others.
	Another positive aspect of the cancer experience related to lifestyle changes that women had made in order to improve their general health and prevent cancer from recurring, including adoption of new health behaviors, such as exercise, quitting smoking, eating a healthier diet, controlling stress, engaging in spiritual practices, and for some, use of complimentary or alternative medicine for others. Social circles of influence inspired survivors' healthcare diligence. Family and friends helped survivors to adjust their schedules, diets, and other health habits for the better.
	Educating oneself by seeking additional information and asking questions, becoming more proactive in their medical treatment, timely follow-up with medical treatment, documenting physical response to medical treatment, obtaining a second opinion, and engaging in a healthy diet and taking exercise were emphasized.
	Some women also communicated an altruistic sense of wanting to 'give back' or help others, to be role models and support those recently diagnosed with breast cancer, out of a sense of gratitude for the help and support they had received during their treatment. This was evidenced in their participation in breast cancer advocacy events and support

Synthesis of Edited Findings: Grief Work	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
	meetings. It was also seen as where they could build ties with the only people who, they believe, can truly understand their experience, women who have "been through it." This level of understanding was not present within women's other relationships, and participants regularly distinguished between those who could "sympathize" but not "empathize."
	While the survivors did not minimize their painful experiences, over the trajectory of survivorship, initially negative perspectives on the breast cancer experience underwent a positive transformation. They reported that overall breast cancer had a positive effect on their lives.
	They identified improvements in the quality of relationships with loved ones and a heightened appreciation and purpose of life
	A common theme running though the narratives was the contribution of spiritual beliefs, to finding strength for dealing with breast cancer, and signaling a turning point in the transition from an initially negative to a positive perspective on the breast cancer experience.
	'Becoming a breast cancer survivor meant finding new roles. Strength, purpose, and a sense of obligation to fill these roles grew from a sense of God's intervention in the process of surviving breast cancer.
Synthesized Finding	*The fifth stage of grieving for the WSBC (Acceptance, reorganization and recovery) is marked by positive aspects of the breast cancer experience. The WSBC described a renewed appreciation of the preciousness of life and a sense of empowerment as they moved on to a "new state of being". They took charge of their lives and their ongoing treatment and made positive lifestyle changes to prevent cancer from recurring. They developed new attitudes towards cancer and those around them, including for some, valuing spirituality and/or religion. The WSBC has moved beyond breast cancer, forever a survivor, but also more. A positive transformation has taken place. They see a heightened appreciation and purpose of life. An altruistic sense of wanting to "give back" is a common theme, as evidenced by participation in breast cancer advocacy events and support meetings. Again, a common theme was the contribution of spiritual beliefs and a sense of God's intervention in their lives.*

Synthesized Findings 6: Identity Work (Role Choice Behavior)

Synthesized Findings: Identity Work – Role Choice Behavior	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
Role Choice Behavior (commitment leads to identity salience leads to role choice)	As a result of feeling permanently 'changed' and unrelenting worries about recurrence, many women expressed discomfort about being called a 'cancer survivor'. WSBC were also consistently surprised when others acted as if the breast cancer experience never happened or treated the experience as "over" following the first year. For participants, the experience was "far from over" because they lived with ongoing reminders and felt changed by it. Survivors usually defined survivorship in relationship to what it meant to experience cancer; these overarching attitudes often shaped their expectations for care. One survivor saw herself as a life-long cancer center patient.
	Assessing the severity of their illness in terms of life or death, participants spent enormous personal resources helping others to cope with their illness with as little burden as possible. Some women spoke of the added burden of being concerned about disclosing their illness, and needing to 'be strong' for family members as they transitioned out of treatment, and pressures to act like a hero (conceal their fears or ongoing symptoms), even though they still had physical or emotional needs. As a result, they were highly selective in the care they sought from others, men as well as women.
	WSBC were faced with family members' challenges adjusting to new roles of being caregivers and her difficulty in reversing roles with her family. Family expectations about the woman's functioning after treatment were a concern expressed by some. A number of Chinese survivors reported that they performed daily chores themselves even during treatments, rather than receiving help from their families, and dealing with associated role conflicts. For African Americans, even with fatigue continued caring for others may have caused, such caring was described as a positive way to cope with the treatment for breast cancer, and caring for others encouraged African American women in their recovery
	Many of the African American participants sought support groups that were designed for African American women with breast cancer because they believed that they wanted to be around women who were like them and traditional support groups sometimes were not sensitive to their needs and concerns.
	WSBC recognized the need to become more individualistic as a necessary coping strategy. However, even when focusing on their individual needs, taking care of themselves, or receiving care from others, they adjust their gendered understandings of themselves in regard to care in order to accommodate deeply felt imperatives to care about and for others. While this action was empowering to some women some of the time, it also caused tension in their lives and ambivalence about their identities as women. The self-interestedness necessary to cope with breast cancer would undoubtedly conflict with the typical gendered role and create added stress. Gender negotiation is reflected in their ambivalence about accepting help from others; negotiating power differentials within their relationships, the desire to take care of themselves, instead of asking for help; and the tendency to engage in supportive relationships with other breast cancer survivors, who are typically thought to be the only people who can truly understand their experience. The ease with which women redefine what they consider to be normal is closely tied to others' expectations.

Synthesized Findings: Identity Work – Role Choice Behavior	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
	Women's responses to breast cancer can be understood as a reflection of dominant cultural scripts that define women as "natural" nurturers. As respondents speak about their experiences with breast cancer both within and outside of the medical realm, their narratives illustrate the salience of gender, particularly as it relates to compliance to others' needs and desires, rather than a prioritization of their own.
	Many women thought of themselves as transformed and truer to themselves as a result of the sudden thrust into the medical system to procure care for themselves. They believed that the authoritarian nature of doctor-patient relationships evoked these gendered responses. In overcoming this, they learned to break from the constraining attitudes and behaviors that were typical of them prior to their diagnosis. Essentially, what women developed was a gender consciousness.
	The narratives reflected a strong call to be of service to others. The phrase, "giving back" was spoken repeatedly. "Giving back" suggests that first something was given to them, and second that they were returning it to the person(s) who gave it. What exactly had they received, what were they giving back, and to whom? The answers to these questions reveal that women's engagement in formal and informal support to other breast cancer survivors stems from an attempt to gain understanding, and to balance the self-interestedness that becomes necessary when responding to their illness. Women "give back" to a community of women with breast cancer to build ties with the only people who, they believe, can truly understand their experience, women who have "been through it." This level of understanding was not present within women's other relationships, and participants regularly distinguished between those who could "sympathize" but not "empathize." As women are socialized into their gender identities, they are trained in empathy in order to have a greater appreciation for what others, particularly loved ones, are experiencing. This helps them to better understand another person's situation, perspective, and problems, i.e., to be better caregivers. It is not surprising then, that women with breast cancer seek empathy from other women (with breast cancer). In the search for empathy, women sought understanding from other women, thereby reinforcing the gendered dimension of social interaction in everyday relationships as well as within the context of breast cancer itself.
Synthesized Finding	*WSBC had difficulty with the term 'survivor' because, their ongoing symptoms and risk factors reminded them that 'survival' was not a given. This placed them in a nether land of what Frank called, "the land of the sick and the well". WSBC experienced and continued to experience breast cancer; it's treatments, resulting symptoms, and a formal release by HCPs back into 'life'. 'Life' is not the same, nor are they. However, WSBC thought of themselves as transformed and truer to themselves as a result of the sudden thrust into the medical system to procure care for them. They believed that they overcame the typical power and gendered responses of dealing with doctors and the medical system. In overcoming this, they learned to break from the constraining attitudes and behaviors that were typical of them prior to their diagnosis. Essentially, what women developed was a gender consciousness. WSBC a new commitment self-interestedness: a sense that they need to take care of themselves, they have a right to experience and enjoy life and be thoughtful of how they spend the rest of their life. Socialization into gender identities required that they be trained in empathy in order to have greater appreciation for others, especially loved ones. As caregivers WSBC expressed the desire 'give back'. By doing so they found empathy and understanding with those that share their experience, which*

Synthesized Findings: Identity Work – Role Choice Behavior	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
	reinforces the gendered dimension of social interaction in everyday relationships, as well as within the context of breast cancer itself. This allows them to connect with and form their new identities through relationships with like-minded others. This can result in role strain if the WSBC were not impacted by gendered role consciousness.

Synthesized Findings 7: Identity Work (Perceptual Control)

Synthesis of Edited Findings: Identity Work – Perceptual Control	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
Identity Disruption: Factors of the physical self (Body image, or stigma/disclosure, or sexual function)	Most women recalled that cancer was not openly discussed in the family during their childhood, and that it was taboo to talk about having cancer. The silence and shame regarding cancer was particularly common in the past and in certain cultures, especially African American and Latina. Disclosure to potential partners, and reservations about dating was a major concern for some African Americans, Latina and Asian Americans. The importance of understanding the historical meanings of "socialized silence" in the African American community cannot be understated. African Americans have been part of and separate from the American society for decades. This separation has led to both strengths and distrust.
	Women from all groups spoke of difficulties in adjusting to physical changes from cancer. Many survivors described negative feelings about their bodies after breast cancer and its treatments. Common sentiments include decreased self-worth and attractiveness, feeling deformed, inadequate, sad, embarrassed, frustrated, and/or a sense of loss. They no longer felt the same way about their bodies, and felt that their bodies had betrayed them and could no longer be trusted. They wrestled with the ideal of feminine beauty and how that related to any future relationships with men. African American, Asian American, and Latina survivors noted that self-acceptance is more difficult for younger women, as there is more emphasis on physical appearance and concern about breast reconstruction. A number of the Latinas' husbands did not accept them after their illness and treatments. Seven were abandoned after being diagnosed. The effect of body image for older women was less problematic. For all groups, feeling that their partners loved them and accepted their new body image (e.g., breast removed) encouraged survivors to also accept their bodies, increasing their feelings of self-confidence.
	African American participants believed that there was a difference between "black women" and "white women" when it came to relationships. Their perception was that black women do not base their lives on their men, and that white women are more dependent upon having men in their lives. They indicated they would rather live without men if it meant sacrificing themselves. If the men could not cope with their breast cancer diagnosis or change in appearance, the women preferred that those men move on.
	Decreased or lack of sexual desire, or function, after treatment was a common problem for the WSBC and was frequently attributed to a decrease in libido or a result of the chemical onset on menopause, and they worried that their interest in sex would never return. Women described feeling unprepared to expect decreased sensation resulting from removal of a breast or nipple, which lessened their sexual arousal. The sense of self as a sexual creature was lost in the experiences of diminished sexual arousal, dry vagina, and loss of breasts. In conjunction with painful intercourse, decrease in desire negatively impacted women's relationships. The women emphasized the importance that their partners continued seeing them as sexually desirable despite their own feelings. Some Korean survivors reported feeling obligated to satisfy their partners' desires despite their lack of desire.
	Weight gain was reported to be very distressing, with many women describing that they

Synthesis of Edited Findings: Identity Work – Perceptual Control	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
	felt that it was easier to gain weight after treatment and that it was more difficult to lose weight. Many stated that they were not prepared for the possibility of gaining weight and would have liked to receive more information about what to anticipate and how to minimize or prevent weight gain.
	The women voiced frustration that their healthcare providers had not included information about these side effects of treatment when telling them about chemotherapy. They discussed changes in their sexual relationships, including the loss of breast sensation and decrease in sexual desire. This had a negative impact on the quality of their relationships with their partners.
	The deviation in appearance (e.g. loss of a breast, or loss of hair due to chemotherapy) as a significant source for feelings of "markedness." When a woman becomes visibly different from everyone else (considering the context of illness), she finds herself positioned as the "other," the "strange," and the "deviant." There is a change in her ordinary way of being as someone who blends in (or, if she is used to standing out, now she becomes noticed in a different way). With this change in her physical body, she is brought forward into the public eye. The woman in this state cannot take her body for granted; nor can she take body-in-the-world for granted. Thus, the concern for her health and any pain or discomfort is accompanied by a public display of markedness, which creates a new, unfamiliar, and self- conscious way of experiencing one's body/self. When she goes abroad among others, she is faced with this sense of alienness … or a sense of loss. Deviance attracts notice, or one feels that it does. However, it is not the change in physical appearance per se that has a meaning or shapes one's actions but the responses of others to it (including the anticipated or imagined responses). This results in the disruption of the flow of interaction and discredits one's social identity. The degree to which one's stigmatized condition interferes with social interaction plays a significant role in the ways in which one experiences the discrediting implications of his/her stigma. When there is a change in our looks, a need to restore the disrupted self-body relation comes about. Some women choose to update their concept of self to match their new looks. However, African American WSBC stated that breasts could not think or make choices, and therefore breasts did not fit their definition of being an attractive Black woman. Beauty was found not in breasts, but in a woman's mind.
	Women indicated that ongoing pain and other symptoms not only took them by surprise but also created apprehensions about cancer recurrence, which made some feel hypochondriacal, frequently calling or visiting doctors because of the need for reassurance. Women sometimes withheld symptom complaints because they feared that they could negatively influence or even risk the loss of relationships with their doctors.
Synthesized Finding	*The word 'cancer' evokes feelings of fear, mortality, taboo, shame and silence. This is especially true in certain cultures, especially African American and Latina. Disclosure to potential partners, and reservations about dating was a major concern for some African Americans, Latina and Asian Americans. This is a disruption in identity that is imposed by the cultural meanings of stigma in the above populations. However, the historical meanings of "socialized silence" in the African American community cannot be understated. African Americans internalized the imposed socialized silence into a means of protection and rebellion against those that marginalized them. African Americans have been part of and separate from the American society for decades, which has led to*

Synthesis of Edited Findings: Identity Work – Perceptual Control	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
	both strengths and distrust. This cultural distinction provided a structural support that is unique to the African American society and resulted in identity outcomes that differed accordingly. All WSBC had difficulty with body image to one extent or another. African Americans, Asian Americans and Latinas thought that this was particularly an issue for younger WSBC who were more concerned with body image. They also felt it might impact their ability have a future relationship with a man. African American women viewed themselves as independent and 'white women' as overly dependent on their men. The African American women expressed that they would not allow their men to determine what treatment course they chose based on body image. Again, this reflects differences amongst Caucasian and African American relational networks. African American WSBC also spoke about the fact that their breasts could not think or make choices, and therefore breasts did not fit their definition of being an attractive Black woman. Beauty was found not in breasts, but in a woman's mind, reflecting a differing social construction of feminine beauty. Latinas were particularly vulnerable due to cultural meanings of "machismo". Indeed, some men rejected them and subsequently left them. Married women felt less challenged by body image when their partners indicated that they loved them no matter what. Older women had fewer issues with body image but it did impact all women in one way or another. This was, for the most part, a disruption to self and created disappointment and sadness of the loss of the body as normal. However, the sense of shame and embarrassment could be also attributed to others, their partners, husbands and for those with no present partners but would have to deal with body image in the future. The salience of relational networks to the WSBC was evident, and the resulting role strain was not unexpected. All the WSBC struggled with sexual issues related to treatment such as surgery or chemotherapy and radiation, each of which impacted and/or was impacted by sexual desire, problems with performance and physical limitations that were painful. These were disruptions that were based in the body but impacted both body and body image and created an identity disruption of self as a sexual being. Women spoke about the fact that HCPs did not prepare them for the sexual issues related to treatment. That said, there is a sense of the spoiled body creating the spoiled identity. There are many reasons to use measures that mitigate that, such as reconstruction. For example, a WSBC does not want to look different at work. She does not want her breast, or lack of it to be the focus. However, there are other reasons why women choose to have radical mastectomies on both breasts, as pre-emptive protective surgery or political statements. Still others use this as an opportunity to enhance their body. Women said that they were taken by surprise by physical symptoms such as pain that they thought might be a sign of recurrence. Some of the women felt hypochondriacal calling or visiting HCPs while others did not want to ruin relationships with HCPs and deferred calling. The unique aspect of the doctor-patient relationship was evident here, as the WSBC at once assumed the role of the compliant patient and dependent woman as a gendered role.
Identity Disruption: Factors of the Psychosocial Self (Ongoing	Once treatment was completed, many women struggled with the pressure to resume family, work, and social responsibilities, and with the burden of needing to "be strong" for family members, precisely at a time when the support provided by others is cut off. Women's guilt about burdening their families and others with their illness contributes to distress, even if the source of burden is clearly outside of their control. They felt pressure

Synthesis of Edited Findings: Identity Work – Perceptual Control	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
symptoms, or life changing nature, or loss of self or control, or pressure to be hero or normal)	to act like a hero (conceal their fears or ongoing symptoms) and sometimes look better than they felt. Even when it did not represent their true experiences, the women reported the pressure in social situations, at work, and with friends and family.
	Participants reported that even their closest confidantes misunderstood how cancer had permanently changed their lives. They portrayed how their spouses, family members, and friends believed that the cancer experience was over when, in fact, it was enduring. This was furthered by the popular discourse about breast cancer survivorship that relegated their experiences to the past (that she had "recovered" or "survived" from a past event) even though the experience was ongoing. Feelings of helplessness arose when women described the unmet need to be seen and affirmed in the reality of their enduring experiences, worries about recurrence and ongoing symptoms. The thought was especially frightening because participants sometimes feared they were becoming estranged from others, which brought a sense of anxiety and loneliness.
	Participants phrased answers by comparing their current health condition to their lives before and during cancer treatment. Survivors also expressed various views about life after cancer including deterministic attitudes, wanting to embrace life to the fullest and evaluating life events in terms of still being alive.
	The shift of perspective from thinking about others to thinking about oneself (the need to become more individualistic) is a necessary coping strategy for managing the life-changing aspects of breast cancer treatments, side effects, interruptions to daily routines, strains on relationships, and existential fears. Feelings of self-confidence, empowerment, or even a new sense of individual identity as women would often conflict with others' expectations. When this occurs, the individuation that was at one time a viable coping mechanism becomes tainted with feelings of selfishness or guilt.
	When coping with breast cancer, respondents evaluate, negotiate, resist, and renew their identities. This process begins the first time a woman breaks from what has been a repeated gender performance of doing care work for others. If gender expectations that stress sacrifice, empathy, and emotional sensitivity sit squarely within a respondent's repertoire then the self-interestedness necessary to cope with breast cancer would undoubtedly conflict with it.
	Participants reported feeling they did not have much control over the disease nor the treatment, and went along with treatment recommendations even though interactions with HCPs were sometimes negative and contributed to distrust. The women voiced frustration that their healthcare providers had not included information about the side effects of treatment when telling them about chemotherapy and did not prepare them for the lingering symptoms. This intensified the women's distress because it led them to question their judgment. Distress was compounded when women felt misunderstood or were accused of feigning or exaggerating their symptom experiences.
	Some women felt a "loss of innocence" and lost sense of "self-distinctiveness". They believed that they would never return to a pre-cancer state in which they could be less somatically focused and anxious. The changes were perceived as carrying a cost to identity.
Synthesized Finding	*The WSBC experienced psychosocial disruptive events, some of which were episodic and others that were on-going. These disruptive events imposed significant role strain upon*

Synthesis of Edited Findings: Identity Work – Perceptual Control	
Conceptual synthesis	**Statements of findings supporting conceptual synthesis**
	the WSBC as they attempted to manage their changing roles within a given social context. The pressure to be inauthentic was greatest during the time following the end of treatment. The nexus of relationships, both at home and abroad, expected them to behave as if they were once again normal, or to take on the role of the "hero" and be strong for others. The on-going nature of symptoms and fears of recurrence were at odds with this expectation and resulted in a significant source of distress, loneliness and alienation for the WSBC. Another source of strain was related to gendered role expectations. WSBC were faced with the need to renegotiate their identities as they shifted form the societally accepted norms of the self-sacrificing, empathetic, emotionally sensitive and nurturing care-giver, to an individualistic and more self-interested care received. This transition, although necessary as a coping mechanism when faced with a life-threatening condition, became an on-going struggle in the process to construct a renewed identity. Similar disconnects between expectations and experience existed within the doctor-patient relationships and other interactions with HCPs. In this case, the WSBC were faced with an added dynamic of power differentials that intensified the gendered role conflict and led to feelings of distrust and loss of control, resulting in guilt and self-blame. However, the process of discovering a renewed identity was not all negative. As the WSBC dealt with the "life changing" nature of BC, positive reappraisal oftentimes emerged. The pre-cancer life was no more, replaced by deterministic attitudes and a renewed appreciation for life and living.

Appendix D: Data Extraction Summaries

Study Demographics	**1**
First Author	Allen
Pub. Date	2009
Title	**The transition from breast cancer ‘patient’ to ‘survivor’**
Affiliation(s)	William Connell School of Nursing Dana-Farber Cancer Institute Harvard School of Public Health
Funding Source	Susan G. Komen for the Cure
Period of Data Collection	Feb-April 2006
Location of Study	Boston, MA
Publication Type/Name	Psychology/ Oncology Psycho-Oncology
Research Problem	While much is now known about breast cancer survivors’ long-term health, quality of life, and psychological state, relatively little is known about the period immediately following completion of treatment, when women transition out of the role of breast cancer ‘patient’ to life as ‘survivor’.
Research Purpose / Objective	To explore women’s fears regarding risk of cancer recurrence, sense of loss of medical monitoring, and social support from health-care providers and other patients, and the strategies they use to cope with these issues.
Orientation towards Target Phenomenon	Interview guide partially based on "Self-Regulation Model". Grounded Theory approach.
Orientation Towards Inquiry	Self-Regulation model used as partial basis for interview guide since it focused on both emotional and cognitive factors that can influence bahavior in the face of a health threat.
Method	
Sampling Strat. / Technique	Recruited from (2) cancer centers in Boston, MA area. (216) eligible, after letter & phone contact, resulted in 47 willing participants. (36 from one center, 11 from the other)
Sample Size / Composition	47 WSBC (Stage I or II) who had completed adjuvant chemo/rad in prior 12 mos.
Ethnic composition / focus	Not specified
Data Collection Techniques / Sources	Focus groups. (5-10 per group, 6 groups)Interviews audio-taped and transcribed. Semi-structured focus group guide.
Data Mgmt / Analysis Techniques	Analyzed using a constant comparative analysis approach. Manual and CAQDA using QRS Nvivo.
Findings	
Logic & Form of Findings	Thematic construction with quantitative identification of positive, negative and neutral comments from participants.

Type / Classification	Conceptual thematic description
Summary of Findings	• Positive life changes as a result of the cancer experience • Fear of recurrence • Emotional distress • Losses associated with the end of treatment • Difficulty returning to "normal life" • termination of treatment can shatter the tentative equilibrium that many cancer patients achieve during treatment. • fear of recurrence is common and persistent.
Discussion/Implications	• Interventions should be provided to women as they complete treatment which (1) provide information about the physical, emotional, and social issues that frequently confront women in the initial post-treatment period; (2) offer opportunities to enhance cognitive and behavioral coping strategies, stress reduction techniques, and methods for soliciting social support from network members; (3) offer opportunities to exchange social support with other survivors ('give back, get back'). • This period may represent an opportune time to capitalize on women's motivation to pursue behavioral goals related to health. • Interventions designed for women in this transition period should also address common concerns such as increasing physical activity levels, improving nutrition, and controlling weight
Stated Study Limitations	• Small (design) • Non-representative sample • Goal to hear from women (with variety of experiences; for in depth exploration of transition process)

Study Demographics	**2**
First Author	Ashing-Giwa
Pub. Date	2004
Title	**Understanding the Breast Cancer Experience of Women: A Qualitative Study of African American, Asian American, Latina and Caucasian Cancer Survivors**
Affiliation(s)	Dept of Psychiatry & Behav Science, UCLA Calif School of Prof Psych, Alliant Int Univ
Funding Source	Department of Defense
Period of Data Collection	Unknown
Location of Study	Unknown
Publication Type/Name	Psychology/ Oncology Psycho-Oncology
Research Problem	Although the psychosocial impact of breast cancer is being studied, there is little information on women from diverse ethnic and socioeconomic backgrounds.
Research Purpose / Objective	The research question addressed in this study is: How do culture and socioecological factors impact HRQOL and psychosocial experiences among women who have survived breast cancer?
Orientation towards Target Phenomenon	Key Informant and WSBC Focus Group Interviews were conducted under a semi-structured format. The purpose of the key informant interviews was to gather information about the breast cancer experiences from knowledgeable, community health professionals and advocates working with diverse populations. The purpose of the focus groups for this study was: (1) to obtain information directly from women who had a breast cancer diagnosis, and (2) to further explore the issues identified in the key informant interviews.
Orientation Towards Inquiry	The investigation intends to provide preliminary information to survivors and health-care providers about the impact of cultural influence (e.g. dietary practices, coping, spiritual practices) and socio-ecological contexts (e.g. life stress, neighborhood, social support) on survivorship.
Method	
Sampling Strat. / Technique	Key Informants: Leaders in communities recruited from health clinics, cancer related orgs, and hospitals. Focus Group participants: recruited from cancer support groups, hospitals and community health clinics. Organized in homogeneous ethnic/ linguistic groupings.
Sample Size / Composition	Key Informants: African American (n = 5), Asian American (n = 5), Caucasian (n = 4) and Latina (n = 6). Total 20. Focus Groups: 34 Asian, 24 African American, and 18 Caucasian and 26 Latina. Total: 102. Focus group size ranged from 4 to 13.
Ethnic composition /	African American, Asian American, Caucasian and Latina

focus	
Data Collection Techniques / Sources	Key Informants: 1 h, face-to-face, audio-taped interviews. Focus Groups: All focus groups were conducted by trained RAs, except the Korean group, which was conducted by the support group leaders. Each audio-taped focus group lasted about two hours.
Data Mgmt / Analysis Techniques	A detailed summary of each audio taped interview was conducted and select quotes were transcribed verbatim. Armenian, Chinese, Korean and Latina focus group discussions were translated into a detailed summary in English before conducting further analyses. Content and theme analyses were conducted using a tabulated matrix of the major issues identified. The matrix allowed for comparative analyses across ethnic group.
Findings	
Logic & Form of Findings	Thematic construction using tabulated matrix to allow for comparative analyses across ethnic groups. Key Informants presented separately from WSBC Focus Groups.
Type / Classification	Conceptual thematic description with interpretive explanations.
Summary of Findings	Key Informants: need for more affordable and accessible care communities must be educated about breast cancer and how to maximize their use of available resources, including the treatment and recovery process it is the responsibility of the health care system to become more culturally responsive by increasing staff diversity, knowledge about community resources and psychosocial service partnership or programs Programs must be culturally and linguistically appropriate, such as community based support groups. Focus Groups: African American, Asian and Latina BCS welcomed and actively participated in support groups that were culturally and linguistically appropriate spirituality is significant to the QOL for BCS African American and Latinas acknowledged profound health care and physical concerns there is an urgent need for health care providers to become more culturally sensitive significant ethnic differences in type of treatments were noted, Asians and Latinas were more like to receive mastectomies and African Americans were the least likely to receive adjuvant therapy body image and sexual concerns were common issues for women across all ethnic groups the financial burden of breast cancer is noted; Latinas in particular experienced serious job disruptions and financial hardships due to cancer and its treatments.

Discussion/Implications	This study accomplishes many goals: It adds to the sparse literature about women of color and breast cancer It enhances our understanding of the psychosocial impact It increases our knowledge of specific cultural influences (e.g. dietary practices, coping) and socio-ecological factors and suggests areas that need further systematic research. More importantly, the study addressed areas that have not been adequately studied before.
Stated Study Limitations	Generalizability: (1) the small sample size; (2) many of the participants were Christians; and (3) about 55% were support group members in urban centers (while this may have increased openness, it may have resulted in potential bias). Further, the convenience sampling employed in this study may have resulted in the selection of a specific subset of BCS and may not capture the extent of the diversity of BCS's experiences.

Study Demographics	3
First Author	Buki
Pub. Date	2008
Title	**Latina Breast Cancer Survivors' Lived Experiences: Diagnosis, Treatment, and Beyond**
Affiliation(s)	Univ of Illinois
Funding Source	Univ of Illinois, Campus Research Board
Period of Data Collection	Unknown
Location of Study	Mid-Atlantic Region
Publication Type/Name	Diversity / Ethnicity Cultural Diversity & Ethnic Minority Psychology
Research Problem	Latina breast cancer survivors are not benefiting from advances in psychosocial interventions. Despite their greater breast cancer burden, there is a dearth of information about this population.
Research Purpose / Objective	Conduct a qualitative study to examine the experiences of 18 immigrant Latina breast cancer survivors along the survivorship continuum, from diagnosis to long-term survivorship.
Orientation towards Target Phenomenon	Health disparities pertaining to breast cancer arise from the institutional, psychosocial, and cultural contexts in which Latinas are diagnosed. Although demand for psychosocial services is expected to increase in coming years, a recent investigation of organizations serving Latina survivors suggests that women are not being adequately served and that few programs are available for this population
Orientation Towards Inquiry	To analyze transcripts, we used grounded theory, a systematic approach that allowed us to consider alternative meanings of the data
Method	
Sampling Strat. / Technique	Latina survivors were recruited from a nonprofit, cancer support organization in the mid-Atlantic region that provides free psychosocial services to Latinas with cancer. Only women with a single breast cancer diagnosis were included; women with a second primary cancer, a recurrence of a primary cancer, or metastatic cancer were excluded because their needs were expected to differ
Sample Size / Composition	Eighteen Latina survivors participated in the study. Their ages ranged from 35 to 67 years (M 51.22, SD 9.58), and their ancestries were Central American (n 8; 44%), South American (n 5; 27%), Mexican (n 3; 17%), Dominican (n 1; 6%), and unknown (n 1; 6%). Participants had lived in the United States, on average, 19.18 years (SD 10.57 years), and displayed low levels of acculturation (M 1.52, SD .37).
Ethnic composition / focus	Latina

Data Collection Techniques / Sources	Facilitators provided summary statements and asked for feedback to provide multiple opportunities for participants to elaborate on their statements. In addition, we analyzed the data in the source language, included a peer researcher, and provided thick description. We increased the dependability of the study by having two persons conducting the analyses. The peer researcher (who had not participated in the data analyses) read a preliminary version of the results and provided feedback to further refine them.
Data Mgmt / Analysis Techniques	Qualitative data were analyzed following grounded theory coding guidelines. A multilevel analysis technique was used, starting with line-by-line analysis (open coding) to ensure all data was accounted for, then axial coding was used to establish conceptual categories, finally themes were identified and their relevance across survivorship stages.
Findings	
Logic & Form of Findings	Thematic construction enhanced by cross reference to relevancy in survivorship stages.
Type / Classification	Conceptual, thematic and temporal description.
Summary of Findings	The data suggest that for Latina immigrants, being a survivor of breast cancer is not a monolithic experience but a process marked by the stressors and tasks that women face at each stage. Acute Stage: Psychol. well-being (PWB) markers included acceptance (of diagnosis), optimism (of a cure) and confidence. Need for social support. Reentry Stage: Transition from diagnosis/treatment to "normalcy" defines PWB. Need for social support, reframing life. Long-Term Survivorship: PWB markers of confidence and optimism. Need for social support, changes in social roles and identity.
Discussion/Implications	Psychosocial interventions tailored to women at each stage are likely to be more effective than generic interventions directed at Latinas at all stages of the cancer experience. Tailored interventions have the potential to help women cope more effectively with their current stressors and tasks, help them anticipate the demands associated with the next stage, and prepare them to face these challenges successfully.
Stated Study Limitations	The subjective experiences of these participants may not reflect the experiences of other Latina survivors who had not contacted a community organization. Also, the fact that participants were foreign born, had barriers to overcome when immigrating to the United States (e.g., language, knowledge of the health care system), and had low acculturation levels may have influenced their reports.

Study Demographics	**4**
First Author	Capiello
Pub. Date	2007
Title	**Breast Cancer Survivors Information and Support After Treatment.**
Affiliation(s)	Yale Cancer Center
Funding Source	Beatrice Renfield-Yale School of Nursing
Period of Data Collection	Aug 2004-Dec 2005
Location of Study	NE United States
Publication Type/Name	Nursing Clinical Nursing Research
Research Problem	Women living with and beyond breast cancer have special health care needs. Persistent physical and psychological symptoms such as fatigue, pain, sleep disturbances, and fear of recurrence as well as quality-of-life outcomes have been described in women during and after breast cancer. Much less information exists on the experience of women completing treatment.
Research Purpose / Objective	This study describes the information and support needs of women following breast cancer treatment.
Orientation towards Target Phenomenon	This study was part of a larger project to develop an information support intervention aimed at enhancing adaptation and promoting self-care in women transitioning from treatment. Theoretical support for this project was drawn from the concepts of symptom distress, quality of life, self-care management, and survivorship.
Orientation Towards Inquiry	A semi structured interview guide was designed by the research team to assess information and support needs of women following breast cancer treatment.
Method	
Sampling Strat. / Technique	The study was conducted at two National Cancer Institute–designated Comprehensive Cancer Centers in the northeastern area of the United States. Participants were recruited through the medical oncology clinics at both institutions. Participants meeting the following eligibility criteria were recruited to participate: those with early-stage (0—IIIA) breast cancer diagnosed within the past 5 years who had completed primary and/or adjuvant treatment (except hormonal therapy), those able to read and speak English, those mentally competent to provide consent, and those who had access to a telephone.
Sample Size / Composition	A total of 24 individuals were approached to participate in the study; of these, 20 women agreed to be interviewed and 4 declined. Participants were predominantly Caucasian (18 out of 20), married, and well educated, and most had health insurance. Mean age 52.

Ethnic composition / focus	Caucasian
Data Collection Techniques / Sources	A semi structured interview guide was designed by the research team to assess information and support needs of women following breast cancer treatment. Content for the semi structured interview guide was derived from relevant literature and investigator experience and aimed to elicit data from survivors on their information and support needs following therapy.
Data Mgmt / Analysis Techniques	Data were collected on the type and amount of information they received in preparation for the transition off therapy and their perceptions of the usefulness of this information. All participant interviews were audiotaped, transcribed verbatim, reviewed, and analyzed by members of the research team. Narrative analysis of the participant's responses was provided.
Findings	
Logic & Form of Findings	Narrative description of findings, grouped in pre-determined categories.
Type / Classification	Topical description.
Summary of Findings	BCS continue to experience a variety of physical and psychological symptoms and have concrete information and support needs The women identified the need for information on persistent treatment side effects, emotional distress, and lifestyle changes. Survivors often feel unprepared for the side effects that linger after therapy. Patients report that they are more likely to obtain cancer information on their own rather than from health care personnel, and the increasing use of the Internet by cancer patients also suggests that oncology providers may not be adequately meeting the information needs of patients.
Discussion/Implications	The findings of this study illustrate the need to provide comprehensive information and support to help prepare women transition from breast cancer therapy. This investigation also supports the need to better prepare women for symptom patterns over time and to provide information related to surveillance, health promotion, and risk reduction
Stated Study Limitations	Small, cross-sectional sample related to reported frequencies of symptoms, yet the size of the sample is consistent with qualitative inquiry. The sample was also relatively homogenous from a racial/ethnic perspective. Another limitation is participants' recall of their symptoms and information and support needs during the 1st year following therapy due to cognitive challenges following treatment.

Study Demographics	**5**
First Author	Gallia
Pub. Date	2009
Title	**Narrative Identity and Spirituality of African American Churchwomen Surviving Breast Cancer Survivors**
Affiliation(s)	School of Nursing, UNC - Chapel Hill
Funding Source	Univ of the Incarnate Word
Period of Data Collection	Unknown
Location of Study	SW United States
Publication Type/Name	Diversity / Culture; Journal of Cultural Diversity
Research Problem	Despite evidence of significant relationships between ethnicity and quality of survival for persons with cancer, few studies have investigated the effects of cultural beliefs and culturally situated life experiences among African American women surviving breast cancer.
Research Purpose / Objective	The purpose of this study was to examine the nature of identity, spirituality, and breast cancer survivorship for African American women who participate in traditional African American churches, using a life story analysis framework.
Orientation towards Target Phenomenon	Breast cancer poses a special health threat to African American women. Breast cancer mortality for African American women exceeds that of other groups, and African American women are more likely to be diagnosed with late stage breast cancer. African American cancer survivors suffer more coexisting health conditions and poorer outcomes of treatment than do other groups. Much research on African Americans and cancer has focused on screening behaviors, revealing a constellation of culturally based beliefs - fear, fatalism, and silence - which operate as barriers to screening in this population.
Orientation Towards Inquiry	McAdams' life story analysis framework was chosen to guide the study. It represents a social constructivist orientation in which reality, knowledge, and meaning are inter-subjective. This stance is congruent with the traditional African American worldview.
Method	
Sampling Strat. / Technique	A convenience sample of women surviving breast cancer was recruited by invitations presented by one of the investigators during church services and by snowball sampling. Each woman identified herself as an active participant in one of the African American churches from which subjects were recruited.
Sample Size / Composition	Eleven (11) WSBC. Time elapsed since the breast cancer diagnosis for these women ranged from one to ten years, with a mean time since diagnosis of seven years. All had been treated with multimodal therapy. Age range 40-84.
Ethnic composition /	African American

focus	
Data Collection Techniques / Sources	Interviews lasting one to two hours were conducted by an African American investigator in the participant's home. Using a semi-structured interview protocol adapted from McAdam's life story interview method. Interviews were audio-taped and transcribed verbatim using a transcription protocol to capture participant's patterns of speech and emphasis. The investigator who conducted the interviews recorded field notes following each interview and checked each transcript against the corresponding audiotape for accuracy.
Data Mgmt / Analysis Techniques	Each interview transcript was reviewed independently by two investigators to develop a core narrative constructed of life story scenes based on the participant's description of self-identified chapters, high points, low points and turning points. McAdam's life story analysis framework and coding scheme (Foley Center for the Study of Lives, n.d.) was used as the basis for directed content analysis of the narratives.
Findings	
Logic & Form of Findings	Narrative form assigned to themes centered on "redemption".
Type / Classification	Conceptual and thematic descriptions.
Summary of Findings	Redemptive narratives: A negative response to the breast cancer diagnosis becomes a positive story of survivorship through affirming existing beliefs in God's guidance awareness of personal strengths embedded in an identity as an African American woman applying lessons learned from facing previous negative life events Themes of agency: Finding direction and strength by focusing on a concept of God's will for her life. Developing a sense of breast cancer survival as a consequence of God's intervention. Themes of communion: Filling culturally directed social roles. Receiving personalized support from a social network including the church pastor. Idealized self-images (imagoes). A woman able to face difficulties with strength drawn from faith and the culture. A woman living out a destiny ordained by God.
Discussion/Implications	Living with cancer has been conceptualized as a process that interrupts the continuity of an individual's sense of identity. Their spirituality served as a means of preserving their identities and gave comfort and direction along the cancer trajectory. Findings of this study offer a picture of cancer survivorship among African American women who participate in the life, values, and belief system of traditional African American churches. The pervasive influence of these women's identities as members of this subgroup of African Americans on their well-being during survivorship suggests that framing research with cohesive groups existing within larger cultural populations can offer a deeper understanding of specific contextual factors that influence clinical

	outcomes.
Stated Study Limitations	Limitations include the small convenience sample and interviewing participants only once. Another consideration may be the small proportion of African Americans in the population of the city where the study took place.

Study Demographics	**6**
First Author	Gonzalez
Pub. Date	2007
Title	**Coping With Breast Cancer: A Qualitative Analysis of Reflective Journals**
Affiliation(s)	Univ, South Fla, College of Nursing
Funding Source	Unknown
Period of Data Collection	Unknown
Location of Study	Unknown
Publication Type/Name	Nursing Issues in Mental Health Nursing
Research Problem	Non-disclosure of emotions has been shown to inhibit individuals' adjustment to illness and formulation of adequate coping mechanisms.
Research Purpose / Objective	The purpose of this qualitative study was to examine responses to the diagnosis and treatment of breast cancer and patterns of coping through an analysis of written reflective journals.
Orientation towards Target Phenomenon	Experiences during the diagnosis and treatment of breast cancer have been described by women as a physical and psychological trauma that reduces the sufferer to a condition of passive acceptance and increased vulnerability Non-disclosure of emotions has been shown to inhibit individuals' adjustment to illness and formulation of adequate coping mechanisms.
Orientation Towards Inquiry	The eight women were part of a larger quantitative study measuring the effect of relaxation and guided imagery on stress and immune status. The study took an ethnographic methodological approach in order to facilitate the rich description of the participants' experiences of breast cancer diagnosis and treatment.
Method	
Sampling Strat. / Technique	Convenience sample of 8 WSBC who agreed to share the contents of reflective journals. Part of a larger (N=34) quantitative study measuring the effects of relaxation and guided imagery on stress and immune status.
Sample Size / Composition	Eight (8) WSBC. All diagnosed with Stage I or II BC, and beyond primary treatment. Age range 44-71. Mean age 58.7.
Ethnic composition / focus	Caucasian
Data Collection Techniques / Sources	The method of data collection was semi-structured diaries that the participants maintained for the duration of the six months of the study.

Data Mgmt / Analysis Techniques	Data analysis followed a framework for analysis based on a 14 stage process, which included intensive data review, open coding, development of categories, coding to categories and validity / bias checking.
Findings	
Logic & Form of Findings	Thematic construction based on a polyvocal representation of the Acute Phase of survival.
Type / Classification	Thematic description with some interpretive explanations.
Summary of Findings	Assumption of an adaptive position: (The way the BCS chooses to deal with the diagnosis & treatment.) Active Coping. Passive Acceptance/Resignation. Emotional Avoidance. The need for tangible evidence of love and support: "I am getting what I need". "I am not Getting What I need." "I Can Give Myself What I Need." The need for something more: The need for more meaningful connections with others. The need for a form of Spiritual Connection There appears to be a link between self-disclosure provided by lengthy diary entries and perceptions of adequate support.
Discussion/Implications	The diaries in this study revealed that women who made lengthier descriptive diary entries were those who had avoided sharing their feelings about the illness and those who perceived themselves as not receiving the support they needed. For these women, the diaries appeared to provide a means for self-disclosure of their reactions and feelings regarding their illness and treatment. Investigation of the use of diaries with a larger, more diverse sample might validate their value as a source of self-support. Moreover, written diaries may provide evidence-based documentation of the efficacy of supportive and cognitive behavioral interventions designed to alleviate psychosocial stress during and after breast cancer treatment.
Stated Study Limitations	Given the small sample size of the present study, it is unclear to what extent the findings generalize to the broader population of breast cancer survivors. However, the psychosocial and quality of life issues revealed in this study are similar to findings in the literature in other studies of the psychosocial needs of breast cancer survivors.

Study Demographics	**7**
First Author	Hamilton
Pub. Date	2004
Title	**Types of Social Support in African Americans With Cancer**
Affiliation(s)	Emory Univ, School of Nursing
Funding Source	Nat. Cancer Instit, Minority Supplement
Period of Data Collection	Unknown
Location of Study	SE United States
Publication Type/Name	Nursing Oncology Nursing Forum
Research Problem	When African American patients with cancer have been included in research, the discovery of presumably lower amounts of social support has led researchers to conclude that African Americans are socially isolated and lacking social support . But what is not clear is whether lower amounts of social support actually result from a lack of resources or the failure to identify them because of cultural differences that are not taken into account.
Research Purpose / Objective	To determine the types of social support that African Americans use to cope with the experience of cancer.
Orientation towards Target Phenomenon	Culture effects the social support experiences of patients with cancer. In addition, African Americans have the highest overall incidence of cancer compared to any other racial or ethnic group in the United States. Even though cancer deaths have declined for African Americans, the cancer mortality rates for this ethnic minority group remain higher than those for any other group. African Americans have the worst morbidity and mortality rates of any group with cancer, yet few studies have examined social support from the perspective of African Americans diagnosed with cancer.
Orientation Towards Inquiry	Grounded theory approach to examine the social support in African American women treated for breast cancer.
Method	
Sampling Strat. / Technique	Participants were sampled from lists of participants who had completed three National Institutes of Health-funded studies in the areas of Breast Cancer and Prostate Cancer. These studies were designed to deliver a psycho-educational intervention to women being treated for breast cancer and men being treated for prostate cancer. The women and men recruited for this study were selected deliberately according to key variables identified as important from the social support literature.
Sample Size / Composition	Twenty-eight participants, including 15 women and 13 men. Demographics of the women: average 60, range 42-87.
Ethnic composition /	African American

focus	
Data Collection Techniques / Sources	In depth, initially unstructured and then progressively more directed interviews in the participant's homes, until data saturation was reached.
Data Mgmt / Analysis Techniques	Constant comparison analysis techniques were used for an in-depth exploration and further understanding of the construct social support from the perception of African Americans with cancer and to discern patterns and variations in the types of support within and across cases. The grounded theory techniques of theoretical sampling and constant comparative analysis were used for typology development.
Findings	
Logic & Form of Findings	Quantitative description assigned to discovered themes.
Type / Classification	Topical survey with some interpretive explanations specific to African American experience.
Summary of Findings	• Emotional: Presence of others; Encouraging words; Distracting activities; Protecting and monitoring • Instrumental: Offers of prayers; Assistance to maintain social roles; Assistance to continue religious practices; Assistance to live at home • Informational: Getting information about what to expect; Validating information received; Assistance to understand information
Discussion/Implications	The findings of this study suggest a need to refine prevalent conceptualizations of social support to include the experiences of African Americans. Investigators who study psychosocial issues among patients with cancer must be more sensitive to cultural differences among ethnic or racial groups. Social support instruments generally have been developed from the perspective of white, middle-class people. Knowledge about the types of social support valued among African American patients with cancer can be used to guide clinicians in the development of more appropriate strategies to promote improved health outcomes for this population.
Stated Study Limitations	A major factor that might have influenced the findings was that participants were sampled from a preexisting subject list of patients with cancer who had completed a psycho-educational intervention in which the intervention itself might have constituted a kind of social support.

Study Demographics	**8**
First Author	Henderson
Pub. Date	2003
Title	**African American Women Coping With Breast Cancer: A Qualitative Analysis**
Affiliation(s)	Johns Hopkins, School of Nursing
Funding Source	Unknown
Period of Data Collection	Unknown
Location of Study	SE United States
Publication Type/Name	Nursing Oncology Nursing Forum
Research Problem	The purpose of the study was to obtain a more in-depth understanding of the coping strategies used by African American women so that culturally sensitive health care and culturally relevant coping strategies could be promoted by healthcare providers.
Research Purpose / Objective	To determine how African American women cope with breast cancer.
Orientation towards Target Phenomenon	Breast cancer reportedly is the second leading cause of cancer deaths among women. African American women have a lower incidence of breast cancer; however, they have a higher mortality rate when compared to Caucasian women. Coping strategies can play a vital role in how African American women adapt to their diagnosis of breast cancer.
Orientation Towards Inquiry	Focus group methodology was used to conduct this qualitative study because African American women reported that this approach provided them with a sense of comfort, an ability to relate to others with common experiences, and an opportunity to share and compare experiences with others, establish relationships, and develop a sense of normalcy in their lives. In addition, qualitative data adds richness to the studies conducted on African American women with breast cancer
Method	
Sampling Strat. / Technique	Purposive sampling technique to recruit participants to provide a rich or dense description of the culture or phenomenon of interest. To be included in the study, participants had to be (a) African American women who reported a confirmed diagnosis of breast cancer, (b) living in the southeastern United States, (c) aged 30 or older, and (d) able to read and speak English. Recruited through support groups for African American women.
Sample Size / Composition	Sixty-six (66) WSBC. Age range 35-76, mean age 52.36 yrs. Average length of time from diagnosis 4.39 yrs.
Ethnic composition / focus	African American

Data Collection Techniques / Sources	Instruments used in this study included a demographic data sheet and a semi structured interview guide. The semi structured interview guide was designed to elicit the participants' descriptions of how they coped with breast cancer. All focus group data were tape-recorded and transcribed verbatim. Participants were allowed to discontinue the study or not answer a particular question at any time. The demographic data sheet took approximately 5–10 minutes to complete, and each group was interviewed for approximately 1.5–2 hours.
Data Mgmt / Analysis Techniques	The researchers used content analysis was to examine the frequency, order, or intensity of the occurrence of words, phrases, or sentences for themes that represented the participants. Themes were categorized based on coping strategies described by the participants.
Findings	
Logic & Form of Findings	Narrative descriptions assigned to discovered themes.
Type / Classification	Thematic survey.
Summary of Findings	Coping strategies described by African American women included relying on prayer, avoiding negative people, developing a positive attitude, having a will to live, and receiving support from family, friends, and support groups. The African American women in this study were eager to discuss how they coped with breast cancer, with the expectation of helping other African American women who may be challenged with a diagnosis of breast cancer.
Discussion/Implications	Because coping strategies have been linked to adaptation to breast cancer, nurses must be able to assess coping strategies used by African American women with breast cancer. Nurses must educate other healthcare professionals regarding what the breast cancer experience means to African American women and encourage an interdisciplinary approach to addressing the psychosocial and educational needs of African American women throughout the breast cancer experience. Nurses should strive to create culturally sensitive support groups that will address the needs and concerns of women from diverse ethnic and racial backgrounds.
Stated Study Limitations	• The potential bias in selecting a sample from breast cancer support groups because researchers might expect these participants to list support groups as a strategy for coping with breast cancer. African American women selected from breast cancer support groups may have differed in characteristics, such as attitude toward breast cancer, from African American women who did not attend a support group. • Only African American women were interviewed; therefore, comparisons could not be made with other racial or ethnic groups. • Women were interviewed only once.

Study Demographics	**9**
First Author	Kantsiper
Pub. Date	2009
Title	**Transitioning to Breast Cancer Survivorship: Perspectives of Patients, Cancer Specialists, and Primary Care Providers**
Affiliation(s)	Johns Hopkins, School of Medicine
Funding Source	American Cancer Society
Period of Data Collection	Oct 2007 - Mar 2009
Location of Study	Baltimore, MD
Publication Type/Name	Medical Journal of General Internal Medicine
Research Problem	Limited research exists regarding views of patients, oncology specialists, and primary care providers (PCPs) concerning breast cancer survivorship care.
Research Purpose / Objective	To qualitatively explore the needs and priorities of breast cancer survivors, oncology specialists, and PCPs.
Orientation towards Target Phenomenon	Qualitative thematic analysis was utilized to assess perspectives among the three participant categories. This approach was developed on the premise that the experience of breast cancer and subsequent survivorship may vary by type of treatment, prognosis (influenced by node status), and culture.
Orientation Towards Inquiry	Qualitative theme analysis was used to explore the data. The major thematic findings within the three participant categories included transitions from initial treatment to follow-up, patient-provider communication, patient needs, provider roles, and survivorship care plans, with selected quotes illustrating the themes.
Method	
Sampling Strat. / Technique	Three sample groups were identified: WSBC, Oncology Specialists and PCPs. • WSBC who had completed their treatment by a year or more were recruited. Participants were assigned to groups based on their node status (i.e., node positive versus node negative) and self-identified racial group (African-American versus Caucasian). Recruitment occurred through advertisement via physicians, breast cancer advocacy groups, churches, and breast cancer support groups. • Oncology Specialists: The first group engaged a convenience sample of providers from Johns Hopkins. The second engaged a convenience sample following a breast cancer specialist conference with providers from the mid-Atlantic region.

	• PCPs: Two groups were recruited. The first group was recruited through e-mail to PCPs in the Johns Hopkins Community Physician network. A participant at a breast cancer continuing medical education course volunteered to schedule the second focus group at her practice.
Sample Size / Composition	• WSBC: Twenty-one (21) female breast cancer survivors participated in five focus group sessions. Twelve 12 survivors were within 5 years of diagnosis, and three survivors were more than 10 years from initial diagnosis. Sixteen 16 participants were Caucasian. • Oncology Spec.: Sixteen (16) specialists represented a diverse professional profile, including medical oncology, radiation oncology, breast radiology, breast surgery, oncology nursing, nurse practitioners, and nurse navigators. • PCPs: Fifteen (15) PCPs represented a diverse practice profile. The first group included four family physicians and one family NP from several practices in suburban and rural Maryland. Participants in the second group were nine internists and one NP in Baltimore. Participants' experience ranged from recently joining a practice to having an established practice for 35 years.
Ethnic composition / focus	Caucasian and African American
Data Collection Techniques / Sources	Nine focus groups were held. Semi-structured discussion guides were developed for the three types of focus groups. Although the guides were worded slightly differently depending on the particular stakeholder group, the topics were parallel in all three guides. The patient guides addressed the medical, social, and psychosocial experiences of transitioning to survivorship and their relationship with different physician groups. A stenographer recorded discussions verbatim. After each session, the researchers in attendance recorded immediate impressions and met periodically thereafter to review transcripts and identify themes.
Data Mgmt / Analysis Techniques	Qualitative theme analysis was used to explore the data. Study team members independently reviewed each transcript and identified the major themes and illustrative quotes. Data from the African-American group were presented as a separate subsection.
Findings	
Logic & Form of	Narrative descriptions assigned to discovered themes.

Findings	
Type / Classification	Thematic survey.
Summary of Findings	• **Survivor Perspectives:** o Survivors Derive Reassurance from Specialty Care and Surveillance (emotional connection, special regard for expertise, ambivalence towards completion of primary treatment … abandonment, reassurance gained from long term monitoring). o PCPs Role in Survivorship Care. (Did not see them as having central role in their cancer care, felt that PCPs did not want to "overstep" their role). o Unmet Needs of Survivors (Neither Onc. Spec. or PCPs addressed concerns related to weight gain, altered body image, hot flashes, sexual dysfunction, etc.). o Use of Cancer Survivorship Care Plans (WSBC saw value in written document for ongoing care plan). o African American WSBC: Effect of historical influences and spirituality (concerns about poor care quality and insurance coverage, fear & suspicion from Tuskegee case, importance of spirituality & personal growth, empowered to help other WSBC, inhibited by social taboos in Af Am communities) • **Oncology Specialist Perspectives:** o Ambivalence Over Discharging Survivors (developed bonds and deep concerns, emotionally invested, protective and possessive, enjoyed positive reinforcement by visits from healthy WSBC). o Use of Cancer Survivorship Care Plans (supportive) • **PCPs Perspectives:** o Ambivalence Over Assuming Survivorship Care Responsibility (assumed WSBC were seeing specialists, were reluctant to assume role of specialist, feared missing recurrence in their patients). o Concern in Managing Specialty Health Needs in a Complex System (did not have ready access or time to access necessary information, concerns over medical-legal implications of oncology follow-up, frustrated by limited or delayed communication with cancer specialists, recommended "re-entry vist" to primary care) o (C) Use of Cancer Survivorship Care Plans (supportive providing the cancer specialists stayed involved)

Discussion/Implications	Survivors expressed that ongoing or “usual” follow-up care is not systematic, is not adequately coordinated between teams of specialty providers, and is focused on a narrow set of concerns. Survivors feared recurrence of disease, and some were reassured by regular blood tests and scans, even though current guidelines do not support their use for asymptomatic patients. Survivors wish to collaborate with providers in making medical decisions and want to receive care plan information directly. Creating a written plan that directly acknowledges psychosocial elements of survivorship to ease the transition may be a subject for future research.
Stated Study Limitations	• Patients who participated may not be representative of all breast cancer survivors, particularly those who were active survivor volunteers or were engaged in advocacy groups. • Recruitment of African-American node-positive women did not result in sufficient numbers to hold a separate focus group. • Providers who participated may have had a special interest in survivorship care and may not be representative of all medical providers. • Patients in the survivor volunteer group, the African-American survivor group, and the provider groups were acquainted with many of their group members prior to the focus group. • Although the results of this study may not be generalizable to all breast cancer patients or to cancer patients in general, qualitative research is not intended to obtain generalizable data.

Study Demographics	**10**
First Author	Kooken
Pub. Date	2007
Title	**"I've Been Through Something" Poetic Explorations of African American Women's Cancer Survivorship**
Affiliation(s)	Bradley University
Funding Source	NIH
Period of Data Collection	Unknown
Location of Study	Unknown
Publication Type/Name	Nursing Western Journal of Nursing Research
Research Problem	Previous research has not adequately explored the influence of culture has on diagnosis, treatment, and outcomes of disease. Understanding cultural perspectives is important to decrease the possibility of unintentional discrimination, also known as disparate impact. Disparate impact is a condition in which there appears to be no intent of discrimination, but nonetheless the results of behavior are similar to intentional discrimination and may contribute to health disparities.
Research Purpose / Objective	To describe the common experiences of African American women breast cancer survivors through poetic analysis.
Orientation towards Target Phenomenon	African American women may have needs that differ from those of Caucasian women, and their symptom management issues may be more complex. Learning the effects that this disease and its treatment have on the women and their personal lives so that they can receive appropriate holistic care is important. The purpose of this pilot study was to identify the personal issues and relationship concerns of African American women who had been treated for breast cancer.
Orientation Towards Inquiry	Empirical phenomenology analysis of the data followed by interpretive (hermeneutic) phenomenology to uncover the "hidden meanings" related to the "other side" of everyday experiences.
Method	
Sampling Strat. / Technique	The sample consisted of three focus groups of African American women. Participants were recruited by an oncology nurse, a cancer specialist health educator, and a community activist through acquaintances in the African American community.
Sample Size / Composition	The participants (N = 21) ranged in ages from 38 to 78 years (M = 59, SD = 9.4). Eight were married or living with a partner. The sample was purposively recruited to reflect a wide range of socioeconomic status. Incomes ranged from less than $5,000 to $75,000 per year. All had survived breast cancer and believed themselves to be free of cancer at the time of the study.

Ethnic composition / focus	African American
Data Collection Techniques / Sources	The focus group sessions were scheduled to last 1½ hr and were stopped at that time.
Data Mgmt / Analysis Techniques	Data was collected in two phases, the initial phase focused on QOL factors in African American BCS, the second phase focused on the participants desire to "share their stories" of survivorship. Method of Primary Analysis—Empirical Phenomenology, based on "Group as a Whole" theory. Method of Secondary Analysis—Interpretive (Hermeneutic) Phenomenology.
Findings	
Logic & Form of Findings	Findings were presented in a narrative form as a polyvocal representation.
Type / Classification	Interpretive explanation.
Summary of Findings	• "The Beginning": o Family history increases vigilance; concerns over body image and effect on future relationships with men o importance of male support o "breasts could not think or make choices" and therefore did not fit their definition of an attractive Black woman o breasts as "decorations" appreciated by men o beauty in the mind, not the breasts. • "No News is BAD NEWS" o Treatment phase is seen as the "long wait" o patients waiting for care described as objects who became invisible. • * "A Psalm of Survival" o Faith is central to Af Am culture in dealing with adversity o Perceived lack of care by HC system countered by "God's care" o coping strategies tied to Bible verses and prayer o fear and doubt overcome by faith & spiritual practice. • "The Pink Ribbon Shield" o Insensitivity of HCP as to limitations of BCS o guarded approach to HCP o use of "symbolic communication", e.g. BCS pin / ribbon to remind HCP of history o "socialized silence": defines Af Am relationship with HCS o reluctance to express dissatisfaction with health care and plans o there is a "price for questioning a HCP" o both "part of" and "separate from" American society leads to both strengths and distrust. • "ERAC" (backwards care) o HCP behaviors that contribute to distrust (being talked about as if not present, feeling that HCP did not want to touch them

	because they are Af Am)
	  - safer to rely on self than HCP
	  - myth of the "strong Black woman" leads to an increased burden on AF Am women to care for themselves.
	- "... Fatigue ... Beyond Tiredness"
	  - Fatigue as an overwhelming issue
	  - fatigue in Af Am women increased by commitments as caregivers to others and family obligations
	  - caring for others also seen as a positive way of coping; greater resistance by Af Am women to seek help in daily chores.
	- "I've Been Through Something"
	  - Survival is a process involving reflective assessment of the process from diagnosis and treatment through to a renewed life
	  - survivors emerge on the "other side" of cancer with a different view.

Discussion/Implications	Although some of the experiences of the participants are similar to those of all women who have survived breast cancer, the examination of this journey through the lens of interpretive phenomenology may give some insights into important cultural and historical experiences and questions that have been raised about the African American experience of surviving breast cancer. The findings in this study may be used to improve culturally competent care for African American women with breast cancer. The women in this study were accurate in their self-discovery of breast cancer and in health care practice African American women’s concerns about breast cancer need to be carefully attended. Practitioners should take great care to document family histories and past experiences of breast cancer for African American women.
Stated Study Limitations	None stated.

Study Demographics	**11**
First Author	Rosedale
Pub. Date	2009
Title	**Survivor Loneliness of Women Following Breast Cancer**
Affiliation(s)	NYU, College of Nursing
Funding Source	Unknown
Period of Data Collection	Unknown
Location of Study	Unknown
Publication Type/Name	Nursing Oncology Nursing Forum
Research Problem	Despite the 2.4 million breast cancer survivors in the United States and millions more worldwide no studies have explicitly investigated the phenomenon of loneliness for women more than one year following breast cancer treatment.
Research Purpose / Objective	To describe the experience of loneliness for women more than a year following breast cancer treatment.
Orientation towards Target Phenomenon	A descriptive, phenomenological study based on Husserl's phenomenology and Streubert's nurse-developed methodology was used to study the phenomenon of loneliness for breast cancer survivors.
Orientation Towards Inquiry	A descriptive, phenomenological study based on Husserl's phenomenology and Streubert's nurse-developed methodology was used to study the phenomenon of loneliness for breast cancer survivors.
Method	
Sampling Strat. / Technique	Participants were recruited from a volunteer list at Reach to Recovery, a cancer survivors' network sponsored by ACS.
Sample Size / Composition	Purposive sample of 13 women, 18 yrs or older, completed active treatment for BC a year or more prior to study.
Ethnic composition / focus	Not Specified
Data Collection Techniques / Sources	Data was collected via a process of audiotaped and transcribed, 90 minute open-ended interviews, which included a demographic and treatment questionnaire, supplemented by researcher field notes and reflexive journal.
Data Mgmt / Analysis Techniques	Analysis was conducted via immersive review of transcripts, comparison with researcher's reflexive journal to facilitate phenomenological reduction to consistent "essences" (critical characteristics / facets of an experience).
Findings	
Logic & Form of Findings	Findings were presented in narrative form describing the essences of the "experience" of survivor loneliness.
Type / Classification	Conceptual description with interpretive explanations.

Summary of Findings	Essences:
	• Emerging Consciousness
	  ○ Loneliness part of the on-going experience
	  ○ awareness grows through realization that others are not aware of the BC experience.
	• Transcending Time
	  ○ others treating the experience as being "over" (when it is far from)
	  ○ being alone with a reality that others did not share awakened loneliness episodically over time.
	• Misunderstanding
	  ○ even closest confidants misunderstood how cancer had changed their lives
	  ○ resultant fear of becoming estranged from others.
	• Inauthentic Mirroring
	  ○ pressure in social situations to act like a hero (conceal fears or ongoing symptoms)
	• Fragile Vital Connections
	  ○ loneliness emerged from crises in connections with others (when people were not there for them in ways expected)
	  ○ recognized the fragility of one's connection with the world (complicated for women since they define themselves in terms of their connections)
	  ○ metaphor of the garden ("when cancer invades the garden it exposes the essential fragility of women's essential connectedness")
	  ○ heightened existential awareness; some relationships no longer reliable
	  ○ paradox of finding meaning, purpose and deepened connections through the crisis of cancer; deepened sense of empathy for suffering of others.
	• Withholding Truth
	  ○ loneliness emerges when a survivor withholds the truth
	  ○ afraid to fully reveal themselves to others
	  ○ chastened themselves for thoughts they characterized as "selfish" or not of a "fighting spirit";

Discussion/Implications	The results revealed a unique description of loneliness for breast cancer survivors. Participants described how they felt alone in the awareness of mortality and invalidated in the experience of ongoing symptom burden, a changed sense of identity and connection, and an altered threshold for distress that pervaded their long-term experience. The portrayal of survivor loneliness could not be explained by any single, theoretical framework. Although existentialist perspectives reflected some aspects of survivor loneliness, study findings highlighted that the acceptance of aloneness that is the cornerstone of the existential pursuit was experienced differently by participants. Implication for nursing extend to Education (helping students explore the phenomenon of loneliness from a variety of theoretical perspectives and examine the long-term nature of BC survivorship); Practice (underscores the importance of communication skills and the use of empathy in nursing assessment); Research (need for future research using grounded theory to develop a theory of loneliness following women's' breast cancer health crisis and its survivor aftermath).
Stated Study Limitations	None stated.

Study Demographics	**12**
First Author	Rosedale
Pub. Date	2010
Title	**Confronting the Unexpected: Temporal, Situational, and Attributive Dimensions of Distressing Symptom Experience for Breast Cancer Survivors**
Affiliation(s)	NYU, College of Nursing
Funding Source	Unknown
Period of Data Collection	Unknown
Location of Study	Unknown
Publication Type/Name	Nursing Oncology Nursing Forum
Research Problem	Although researchers have reported significant prevalence of ongoing symptom experience by breast cancer survivors little research has examined how women perceive ongoing, unexpected, and distressing symptom experiences.
Research Purpose / Objective	To describe women's unexpected and distressing symptom experiences after breast cancer treatment.
Orientation towards Target Phenomenon	Uncertainty, feelings of vulnerability, and high levels of emotional distress have been reported in breast cancer survivors in the years after active treatment. Survivors experienced increased psychological distress and worsened health outcomes when they felt unprepared about what to expect in survivorship.
Orientation Towards Inquiry	A phenomenology method was used in the original study, which focused on survivor loneliness. In this study, all participants reported that they withheld aspects of their symptom experience to shield others from the reality that they faced even when doing so contributed to their sense of loneliness. The current study used secondary qualitative analysis to examine the original data set and answer a different question. Secondary interpretation of the researcher's own database answers the question, "What are the breast cancer survivors' experiences of unexpected and distressing symptoms in the years following breast cancer treatment?"
Method	
Sampling Strat. / Technique	Participants were recruited from a volunteer list at Reach to Recovery, a cancer survivors' network sponsored by ACS.
Sample Size / Composition	Purposive sample of 13 women, 18 yrs or older, completed active treatment for BC a year or more prior to study.
Ethnic composition / focus	Not Specified

Data Collection Techniques / Sources	Data was collected via a process of audiotaped and transcribed, 90 minute open-ended interviews, which included a demographic and treatment questionnaire, supplemented by researcher field notes and reflexive journal.
Data Mgmt / Analysis Techniques	The study used secondary qualitative analysis to examine the data from the (2009) Rosedale study to answer a different question. The data was reviewed by a team of researchers to establish relevant codes and develop major themes.
Findings	
Logic & Form of Findings	Findings were presented in a narrative form assigned to developed themes.
Type / Classification	Thematic description with interpretive explanations.
Summary of Findings	• Living with Lingering Symptoms: o felt surprised that the symptoms (e.g. pain, fatigue, impaired limb movement, and poor memory or concentration) experienced during treatment never disappeared but remained part of their lives o ongoing pain not only took them by surprise but also created apprehensions about cancer recurrence o continued cognitive problems believed to be related to chemotherapy treatments o energy levels post-treatment never returned to pre-cancer levels o anger and disappointment arising from loss of energy o lack of preparation for on-going symptoms blamed on lack of proper counseling or deliberate withholding of info o lack of preparation leads to questioning self-judgment and resultant distress. • Confronting Unexpected Situations o feeling a loss of control over one's body and triggered fears of a cancer recurrence o lack of preparation for such instrumental challenges intensified distress o women felt misunderstood or were accused of feigning or exaggerating their symptom experiences o limitations particularly distressing when they had impact on child care o unprepared to expect impacts to sexual function (decreased sensation, vaginal dryness, "un-lifelike" breasts after reconstruction, lessened sexual arousal). • Losing Pre-Cancer Being o “loss of innocence “that they would never return to a pre-cancer state in which they could be less somatically focused and anxious” o did not feel the same way about their bodies again o felt betrayed by their bodies o lost sense of self-distinctiveness (carrying a cost to identity)

	- sense of self as a sexual creature was lost. • Feeling Like a Has-Been - spouses, family members, and friends believed that the cancer experience was over when, in fact, it was enduring - popular discourse about breast cancer survivorship relegated their experiences to the past (that she had “recovered” or “survived” from a past event) even though the experience was ongoing - Feelings of helplessness arose when women described the unmet need to be seen and affirmed in the reality of their enduring experiences.
Discussion/Implications	In this study, as women sought to integrate the cancer experience into their continuing lives, they confronted myriad unexpected challenges for which they felt unprepared. Findings show that the temporal dimension of symptom distress comes from lingering symptoms that the women expected to disappear. The lack of preparation for lingering symptoms intensified the women’s emotional responses (distress) to the symptoms. The ways breast cancer survivors perceive ongoing and unexpected symptoms influence their quality of life. Clinicians should explore the needs of women after treatment and examine the process that frames expectations about survivorship. To decrease distress, clinicians should prepare women for the ways symptoms may play out in their lives. Follow-up care should include discussion about the ways that symptoms can emerge, situations that can occur, and how to live with symptoms.
Stated Study Limitations	None stated.

Study Demographics	**13**
First Author	Roundtree
Pub. Date	2010
Title	**Problems in transition and quality of care: perspectives of breast cancer survivors**
Affiliation(s)	Univ of Texas, Anderson Cancer Center
Funding Source	Texas Med Ctr, Lamar Fleming/OH Dav Funds
Period of Data Collection	2008
Location of Study	Univ of Texas, Anderson Cancer Center
Publication Type/Name	Cancer Support Care Cancer
Research Problem	Our qualitative study is among the few that solicit participants' own opinions and attitudes about their current healthcare utilization, screening, and information needs. We anticipated that asking survivors themselves to qualitatively share their needs about survivorship care would reveal areas for quality improvement unexplored by prior studies.
Research Purpose / Objective	To conduct a qualitative study to explore breast cancer survivors' perceptions and attitudes about their current healthcare utilization, screening, and information needs.
Orientation towards Target Phenomenon	It was anticipated that asking survivors themselves to qualitatively share their needs about survivorship care would reveal areas for quality improvement unexplored by prior studies.
Orientation Towards Inquiry	Grounded theory methods were used to analyze focus group transcripts. Themes were identified as they emerged from the data.
Method	
Sampling Strat. / Technique	Potential participants were identified from the Tumor Registry at the University of Texas MD Anderson Cancer Center, a comprehensive electronic database of all patients seen at this institution. adult survivors with an initial diagnosis of breast cancer in the year 2000, treated and without a recurrence as per medical record. Patients identified as eligible were mailed a solicitation letter asking them to participate in a focus group.
Sample Size / Composition	Focus groups included 33 participants, the majority of whom were white (84.8%), college-educated (66.7%), and covered by private medical insurance (75.7%) or Medicare (27.3%).
Ethnic composition / focus	Caucasian
Data Collection Techniques / Sources	Trained moderators hosted all focus groups. Moderators used a script of questions organized into seven original themes. Sessions were audio-recorded and transcribed each focus group. Assistant moderators took notes that were used for checking the accuracy of transcriptions.

Data Mgmt / Analysis Techniques	Grounded theory methods were used to analyze focus group transcripts. Transcripts were imported into NVivo© to record consensus themes, tally code frequencies, and run queries on code relationships. To ensure data reached theoretical saturation, a constant comparison method was used. No new themes emerged by the end of the analysis.
Findings	
Logic & Form of Findings	Findings were presented in narrative form assigned to themes that emerged as a result of grounded theory development.
Type / Classification	Thematic description with interpretive explanations.
Summary of Findings	• Personal Experiences: o Facing barriers to screening (physical and logistical problems) o Feeling in Limbo in the HC System (no providers exclusively devoted to their care other than specialists, felt dismissed by cancer specialists at time of care transfer, perceived reluctance of PCP to take over care from specialists, repetitive transfer may degrade quality of care) o Communicating with Providers (communication problems, lack of attention, lingering unanswered questions) o Determining if current health problems are cancer-related- Using non-prescribed remedies • Personal Attitudes: o Perception of survivorship ("life-long" cancer patient, deterministic attitudes regarding "life after cancer", loss of control, survivorship infuses life with more value o Recurrence concerns (fear of recurrence, heightened tension regarding follow-up calls from physicians, test results, etc.) o Retrospective self-perception (comparing life before cancer to current) o Self-agency (more proactive, asserting their will as to treatment preference) • Social Influences: o Modeling behaviors of others (contrasting responses, some were influenced by others, others were ambivalent) o Weighing effects on family (importance to screening and healthcare in terms of other family members) o Weighing the social effects of care (inspired by social circles of influence, support of significant others in assessing health, late effects hindered social activity, e.g. loss of sexual drive)

Discussion/Implications	This qualitative study was conducted to evaluate the perceptions and specific needs with respect to the healthcare of female survivors of breast cancer. Three overarching themes emerged during the focus groups. These themes are related in a way that parallels Bandura's social cognitive theory of three, interdependent, mutually influential factors integral in developing, sustaining, and intervening upon behavioral patterns—behavior, personal factors, and environmental factors which were aligned with the emerged themes of this study - personal experiences, personal attitudes and social influences respectively. The study provides healthcare professionals with first-hand information from patients with which to broaden and improve patient–provider communication and enhance healthcare delivery in the transition to survivorship care. The findings suggest that a multifactorial, holistic approach to healthcare would achieve better results than merely an administrative one.
Stated Study Limitations	The study is limited insofar as it is qualitative and is therefore not generalizable. It cannot map the causality linking reciprocally-related codes. The sample was very homogeneous, and did not organize focus groups by participant demographics.

Study Demographics	**14**
First Author	Sulik
Pub. Date	2007
Title	**On the Receiving End: Women, Caring, and Breast Cancer**
Affiliation(s)	Vassar College, Dept. of Sociology
Funding Source	Unknown
Period of Data Collection	2004-2006
Location of Study	NE United States
Publication Type/Name	Sociology Qualitative Sociology
Research Problem	This research highlights the importance of the specificity of health contexts in shaping women's sense of empowerment and constraint when negotiating their identities as women to cope with illness.
Research Purpose / Objective	To examine how women with breast cancer define and manage their care needs when facing this illness.
Orientation towards Target Phenomenon	Assumptions regarding women's gendered caretaking behavior (made both by women themselves and by others) are often taken for granted, and a diagnosis of invasive breast cancer can call them into question. Gender identity is socially constructed through interaction, negotiation, and interpretation of one's actions in terms of broader gendered social expectations.
Orientation Towards Inquiry	Data was gathered over a 3 year period using observation and intensive interview techniques, and a grounded theory approach to qualitative analysis. Theoretical sampling strategy was used to further develop the grounded theory.
Method	
Sampling Strat. / Technique	Participants were recruited from several sources, including community-based breast cancer organizations, support groups, the Komen Race for the Cure and other breast cancer community events, public bulletin boards, and through referrals. An initial sample base for in-depth interviews was later expanded based upon a purposive sampling of three theoretical categories.
Sample Size / Composition	In-depth interviews conducted with 14 participants. Subsequent interviews were conducted with 60 BCS recruited from three distinct categories, (1) Members of a breast cancer education/advocacy organization that stresses social, behavioral, and environmental causes of breast cancer; (2) Members of breast cancer support groups focusing on empowerment, social support, fundraising toward cure, and the normalization of breast cancer; and (3) Women who are unaffiliated with any formal breast cancer-related organization. Age range 31-79, mean age 53.6. Caucasian (90%), minority (10%).
Ethnic composition / focus	Not Specified

Data Collection Techniques / Sources	All interviews were audio-taped and transcribed. Data collection and analysis was conducted simultaneously to support iterative modification of the interview schedule as themes emerged.
Data Mgmt / Analysis Techniques	Preliminary theoretical categories were identified through the initial 14 interviews. Subsequent analysis of 60 interviews was performed, consistent with grounded theory methodology, through constant comparison and development of emerging themes.
Findings	
Logic & Form of Findings	Findings were presented in narrative form assigned to themes that emerged as a result of grounded theory development.
Type / Classification	Thematic description with interpretive explanations.
Summary of Findings	Women with breast cancer are frequently not accustomed to the self-interestedness required to cope with a major illness. Even when focusing on their individual needs, taking care of themselves, or receiving care from others, they adjust their gendered understandings of themselves in regard to care in order to accommodate deeply felt imperatives to care about and for others. • Breaking Gender Norms: ("I've become more of a 'me, me' person") o breaking from feminine norms to cope with BC o becoming self-interested, assertive and self-reliant o conflicts with gender role of "nurturer" o the need to become more individualistic as a necessary coping strategy o wanting agency in medical interactions to counter gender responses by medical pers. o BC as impetus for breaking gender constraints o feelings of self-confidence, empowerment, etc. conflict with other's expectations o self-reliance shields others from burden of caring • Renegotiating Identity: ("I'm very gray now about who I really am") o when coping with BC women evaluate, negotiate, resist and renew their identities o need to develop a new sense of normalcy and sense of self-guilt about burdening others contributes to distress o taking blame for situations outside their control • Re-inscribing Gender Norms: ("Giving back") o conflict between women's needs for themselves and internalized scripts to yield to needs and expectations of others o women's engagement in formal and informal support to other breast cancer survivors stems from an attempt to gain understanding, and to balance the self-interestedness that becomes necessary when responding to their illness o "Peers" redefined as BC as the "great equalizer"

Discussion/Implications	Gendered identities shape breast cancer survivors' perceptions of their care needs, how these women reconstruct their identities and self-presentation to manage their needs, and ultimately how they make use of the illness to recast themselves as nurturers within the broader collectivity of breast cancer survivors. Additionally, focusing on breast cancer as a case makes visible how illness itself can be gendered, further intensifying the impact of gendered social scripts on women and influencing their perceptions and coping strategies. Additional research is needed into the language women and men use to speak about illness and assign it meaning. More research is needed about how women with chronic illness balance their needs with the needs of others to maintain a focus on them. Finally, more research is needed into the comparative responses to illness between men and women.
Stated Study Limitations	None stated.

Study Demographics	**15**
First Author	Ucok
Pub. Date	2005
Title	**The Meaning of Appearance in Surviving Breast Cancer**
Affiliation(s)	Hofstra Univ, Dept. of Speech, Commun.
Funding Source	Unknown
Period of Data Collection	Unknown
Location of Study	New York
Publication Type/Name	Sociology Human Studies
Research Problem	Few have empirically studied, however, how women experience beauty and appearance in their daily lives. Keeping in mind the limitations that social structures (i.e., institutions) and culture put on the negotiations of individuals, this paper emphasizes how bodily appearance implicates social interaction and, thus, one's self, in surviving a life-threatening illness.
Research Purpose / Objective	This paper examines the reported experiences of some breast cancer survivors to find out about the implications of changes in physical appearance due to radiation, chemotherapy or surgery for the survivors and their interactions with others.
Orientation towards Target Phenomenon	In line with some recent studies that emphasize the importance of embodied meanings in social interaction and face-to-face communication, this study recognizes the significance of the body in human meaning-making processes and contributes to the emerging studies that explore the relation of the body, self, and social interaction. Unlike studies that analyze the body as a symbol or text disconnected from the actual body (i.e., a representation), this study does not separate appearance from the body.
Orientation Towards Inquiry	For the purpose of this analysis, a definition of self was used as a social process formed in interaction with others. Builds on the work of George Herbert Mead's explication of social self-providing a framework for understanding the meaning(s) attached to physical appearance through the responses of others, and Maurice Merleau-Ponty's work arguing that all human experience comes out of our bodily position, and emphasizes bodily experience as the source of selfhood. Finally, it relies on Goffman's concepts of "presentation of self" and "stigma" in discussing the meanings of appearances that result from social interaction with others and their implications for one's self.
Method	

Sampling Strat. / Technique	This study was part of a larger ethnographic study that is based in observation, participant-observation, interviews and images. The focus here was mainly on the interviews conducted with eighteen breast cancer survivors (including two phone interviews). Due to the private and sensitive nature of the research topic, an intermediary who knew that a potential participant was a cancer survivor (e.g., the director of a cancer related organization, a cancer advocate) helped find interviewees. The intermediary provided information about the study, the researcher's name, and contact information to the people who had already identified themselves as cancer survivors to her. After getting the consent of the survivors through the intermediary, appointments were made for interviews with them.
Sample Size / Composition	Eighteen (18) WSBC. The average age was fifty-three, thirty-seven being the youngest and seventy-four the oldest. Fifteen of the women had completed their treatments. Two women were still being treated with a drug called Tamoxifen, which is usually used for five years following radiation or chemotherapy, and one woman was still going through radiation.
Ethnic composition / focus	Not Specified
Data Collection Techniques / Sources	Individual interviews varied between approximately thirty minutes up to two hours. The interviews took place in the participants' homes or in the researcher's private office, depending on the preference of the participant.
Data Mgmt / Analysis Techniques	For the purpose of this analysis, a definition of self as a social process formed in interaction with others was used. The approach was one of ethnographic study.
Findings	
Logic & Form of Findings	Findings were presented in narrative form assigned to pre-determined themes.
Type / Classification	Thematic description with interpretive explanations.

Summary of Findings	• * Bodily Appearance and Social Interaction o - feelings of "markedness" … when a woman becomes visibly different from everyone else (considering the context of illness), she finds herself positioned as the “other,” the “strange,” and the “deviant.” o it is not the change in physical appearance per se that has a meaning or shapes one’s actions but the responses of others to it (including the anticipated responses) o When one’s bodily presence violates the expectations of an audience, as a bald female does, it might result in the disruption of the flow of interaction and discredit one’s social identity. o Effects of Mastectomy on Social Interaction (feelings of vulnerability due to not having one or both breasts o "visibility" of a particular stigma influences the implications of it on one's self-presentation and social interaction • * Bodily Appearance and Self o Change in appearance that implicate social interaction might transform one's self o hair loss is not just a change in appearance, but is a loss of self o How a BCS experiences herself in terms of the visual features of her body in interaction with others is disrupted
Discussion/Implications	From the stories of the participants, it became evident that problematic situations bring out the relevance of our bodily presence to social interaction. A nonconforming physical appearance, for instance, calls attention to one’s body and makes it relevant to social interaction. Furthermore, it might disrupt the routine of the interaction, resulting in uneasiness, stigmatization, and consequently, alienation from one’s body. The accounts of survivors indicate that supportive social interactions and external validation, such as committed friendships, a spouse or a partner who shows understanding, intimacy and love regardless of one’s altered body, siblings who communicate that you are most valuable no matter how you look, and positive public reactions as one goes about one’s usual everyday business, allow one to move beyond attachment to a prior concept of who one is, and make peace with the present experience of one’s new body. Future research exploring attachment and selfhood, and inquiring the possibility of constructing more expansive, more spacious ways of experiencing self, might be very informative and useful in facilitating healing.
Stated Study Limitations	None stated.

Study Demographics	**16**
First Author	Wilmoth
Pub. Date	2001
Title	**Accept Me for Myself: African American Women's Issues After Breast Cancer**
Affiliation(s)	UNC, Charlotte, College of Nursing
Funding Source	UNC, Elinor Caddell Scholarship
Period of Data Collection	Unknown
Location of Study	SE United States
Publication Type/Name	Nursing Oncology Nursing Forum
Research Problem	African American women may have needs that differ from those of Caucasian women, and their symptom management issues may be more complex. Learning the effects that this disease and its treatment have on the women and their personal lives so that they can receive appropriate holistic care is important. The purpose of this pilot study was to identify the personal issues and relationship concerns of African American women who had been treated for breast cancer.
Research Purpose / Objective	To identify the personal issues and relationship concerns of African American women who are breast cancer survivors.
Orientation towards Target Phenomenon	Breast cancer treatment, especially chemotherapy, has a major impact on sexual physiologic functioning. Research on how women manage these alterations has been conducted with samples composed primarily of Caucasians. Caucasian women generally are diagnosed with cancer in earlier stages than minority women and might be assumed to require less extensive treatment. Little is known about the personal lives of minority women and their intimate relationships after a breast cancer diagnosis.
Orientation Towards Inquiry	African American women have lower incidence rates of breast cancer than Caucasian women yet have higher mortality rates. Breast cancer in African American women tends to be diagnosed in later stages of the disease, and it may be assumed that more radical treatment is needed, which may have more severe side effects. This suggests that African American women may have needs that differ from those of Caucasian women, and their symptom management issues may be more complex. Learning the effects that this disease and its treatment have on the women and their personal lives so that they can receive appropriate holistic care is important.
Method	

Sampling Strat. / Technique	Potential participants were recruited from churches serving the African American community and from the Susan G. Komen Foundation’s Race for the Cure. Study notices were worded to facilitate inclusion of a broad variety of women and to describe the study in terms that were appropriate for church bulletins. The study was described as discussions that would focus on personal issues after breast cancer treatment. African American nursing students displayed a poster describing the study and recruited volunteers for the subject pool.
Sample Size / Composition	A total of 24 women were recruited from churches and the community; 16 women participated in focus groups. Participants were between the ages of 30 and 75, middle to upper-middle class, and all had private insurance. Their cancers had been diagnosed between six months to five years prior to the study.
Ethnic composition / focus	African American
Data Collection Techniques / Sources	Two focus groups were formed; the first consisted of two women who attended both sessions, and the second had 12 women who attended the first session, with 6 returning for the second. Several participants had work conflicts that prevented them from attending the second session; others indicated they would attend but did not. Follow-up telephone calls indicated they had forgotten to include the date in their schedules. Two women were interviewed one-on-one because of travel limitations.
Data Mgmt / Analysis Techniques	Data analysis followed the principles of content analysis. A research assistant compared transcribed interviews to the audiotapes for accuracy of transcription. Then, each team member read every transcript and performed initial coding of meaningful phrases using in vivo codes. The team met to identify meaningful themes and to construct idea categories, selecting terms at a concrete level. Negotiation occurred to determine the actual representation of the women’s words when interpretations were different. Subthemes then were identified that supported the major themes. A frequency count of the subthemes was conducted to determine the most commonly occurring personal issues within this group of women.
Findings	
Logic & Form of Findings	Findings were presented in a narrative form assigned to developed themes.
Type / Classification	Thematic survey.

Summary of Findings	- * Body appearance:
	  - Total body hair loss
	  - Keloid formation
	  - Unbalanced appearance
	  - Color of prosthesis
	- Social support:
	  - Sources of support
	  - Communication issues
	  - Support groups
	- Health activism:
	  - Inform others of risk
	  - Need for education
	  - Teach breast self-examination
	- Menopause:
	  - Cessation of menses
	  - Vaginal dryness
	  - Hot flashes
	  - Sleep loss
	  - Changes in sexuality
	- Learning to live with a chronic illness:
	  - Change in priorities
	  - Daily struggle
	  - Survival

Discussion/Implications	This study documents the personal and sexual concerns of African American women after being diagnosed with breast cancer. These women had concerns that are similar to those voiced by Caucasian women with breast cancer, yet they also expressed issues unique to African American women. These issues included predisposition to keloid formation, lack of prostheses readily available in their skin tones, and urgency in educating other African American women about the risk for breast cancer. The data from this study should be used to provide direction for further research in this area. This topic was clearly of interest to these women, and they were adamant that Caucasian nurses hear them so that culturally appropriate care can be provided.
Stated Study Limitations	The limitations of these data include the small number of participants in the focus groups and the lack of demographic data. The majority of the women was middle-aged and employed with private insurance. Thus, the findings may not be applicable to women of lower socioeconomic status, to those who do not have private insurance, or to women younger or older than those who participated in this study.