

© 2012 by the Oncology Nursing Society. Unauthorized reproduction, in part or in whole, is strictly prohibited. For permission to photocopy, post online, reprint, adapt, or otherwise reuse any or all content from this article, e-mail pubpermissions@ons.org. To purchase high-quality reprints, e-mail reprints@ons.org.

Reclaiming Life on One's Own Terms: A Grounded Theory Study of the Process of Breast Cancer Survivorship

Deborah Witt Sherman, PhD, APRN, ANP-BC, ACHPN, FAAN,
Mary Rosedale, PhD, PMHNP-BC, NEA-BC, and Judith Haber, PhD, APRN, CS, FAAN

Breast cancer survivors comprise about 25% of all cancer survivors in the United States (American Cancer Society [ACS], 2012). An estimated 226,870 women are diagnosed with invasive breast cancer and an additional 63,300 women are diagnosed with in situ breast cancer in the United States annually (ACS, 2012). With the incidence rate continuing to rise but the overall five-year survival rate having improved for all stages, an increasing number of women with breast cancer are living longer than ever. For many, effective screening and treatment have transformed breast cancer into a chronic illness.

For women who have completed treatment, the literature suggests that symptoms of physical and psychological distress pervade the longer-term experience (Cartwright-Alcares, 2004; Fu & Rosedale, 2009; Knobf, 2002; Rosedale & Fu, 2010; Samarel, Tulman, & Fawcett, 2002; Schmidt & Andrykowski, 2004; Thomas-MacLean, 2005; Tulman & Fawcett, 2002), and long-term survivors of breast cancer have continued informational and emotional needs (Vivar & McQueen, 2005). For years following breast cancer diagnosis, many women continue to experience pain (Gil et al., 2004; Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2005), fatigue (Gil et al., 2004), symptoms associated with premature menopause (e.g., sweats, hot flashes, sexual difficulties, fertility issues) (Ganz et al., 2002; Thomas-MacLean, 2005), changes in body image (Thomas-MacLean, 2005), and lymphedema-related symptoms (Fu & Rosedale, 2009). On an emotional level, many breast cancer survivors still express uncertainty (Dirksen, 2000; Sammarco, 2001; Tomich & Helgeson, 2002), emotional distress (Aranda et al., 2005; Carlsson, Arman, Backman, & Hamrin, 2005;

Purpose/Objectives: To develop a substantive theory of the process of breast cancer survivorship.

Research Approach: Grounded theory.

Setting: A LISTSERV announcement posted on the SHARE Web site and purposeful recruitment of women known to be diagnosed and treated for breast cancer.

Participants: 15 women diagnosed with early-stage breast cancer.

Methodologic Approach: Constant comparative analysis.

Main Research Variables: Breast cancer survivorship.

Findings: The core variable identified was Reclaiming Life on One's Own Terms. The perceptions and experiences of the participants revealed overall that the diagnosis of breast cancer was a turning point in life and the stimulus for change. That was followed by the recognition of breast cancer as now being a part of life, leading to the necessity of learning to live with breast cancer, and finally, creating a new life after breast cancer. Participants revealed that breast cancer survivorship is a process marked and shaped by time, the perception of support, and coming to terms with the trauma of a cancer diagnosis and the aftermath of treatment. The process of survivorship continues by assuming an active role in self-healing, gaining a new perspective and reconciling paradoxes, creating a new mindset and moving to a new normal, developing a new way of being in the world on one's own terms, and experiencing growth through adversity beyond survivorship.

Conclusions: The process of survivorship for women with breast cancer is an evolutionary journey with short- and long-term challenges.

Interpretation: This study shows the development of an empirically testable theory of survivorship that describes and predicts women's experiences following breast cancer treatment from the initial phase of recovery and beyond. The theory also informs interventions that not only reduce negative outcomes, but promote ongoing healing, adjustment, and resilience over time.

Cartwright-Alcares, 2004; Samarel et al., 2002; Trunzo & Pinto, 2003), and loneliness (Rosedale, 2009). Women may feel pressured to project false fronts and depict themselves as better than they actually feel for the benefit of health providers (Arman, Rehnsfeldt, Lindholm, Hamrin, & Eriksson, 2004), family members, and friends (Rosedale, 2009; Sinding & Gray, 2005). Although breast cancer often is a woman's first encounter with mortality, a paucity of research addresses the existential nature of the breast cancer survivor experience.

Openness about cancer today has shifted attitudes and reduced cancer stigma, but has encouraged a normalcy narrative following acute treatment. That narrative may promote adjustment and recovery, but also may marginalize the ongoing needs and concerns of breast cancer survivors (Rosedale, 2009). For example, *New York Magazine* (Gluck, 2007) featured photos of 143 smiling and ostensibly robust, healthy cancer survivors on its front cover. Although most research has focused on the immediate adjustment period for women with breast cancer (Boehmke, 2004; Golden-Kreutz & Andersen, 2004), a limited number of studies have given insight into the process of breast cancer survivorship and the ways in which the experience develops and unfolds over time. However, some studies have reported that women with breast cancer seek to find a sense of personal meaning, growth, and hope through the experience (Arman et al., 2004; Hoybye, Johansen, & Tjornhoj-Thomsen, 2005; Landmark, Strandmark, & Wahl, 2001; Nelson, 1996).

Cancer survivorship is viewed as a dynamic and changing process that begins at time of diagnosis and continues for the balance of life (Nelson, 1996). Changed public attitudes and the ever-increasing need to understand survivorship suggest the imperative of developing an empirically testable theory of survivorship that (a) describes and predicts women's experiences following breast cancer treatment from the initial phase of recovery and beyond and (b) informs interventions that not only reduce negative outcomes, but promote ongoing healing, adjustment, and resilience over time. The absence of an empirically testable theory of survivorship is a significant gap in the literature. Grounded theory provides an opportunity to understand women's health phenomena in relation to the symbolic meanings of those situations, with consideration of how those factors affect women's lives and interactions. This grounded theory study aimed to fill that gap in the literature and construct a substantive theory of the process of survivorship for women with breast cancer.

Methods

Design

Strauss and Corbin (1998) stated that "the grounded theory approach is a qualitative research method that

uses a systematic set of procedures to develop an inductively derived grounded theory about a phenomenon" (p. 24). A grounded theory approach was useful in examining women's health phenomena as it challenges reductionistic perspectives and requires the researcher to understand women's experiences within the context of social relationships (Health Care for Women International, 2001). The roots of grounded theory are found in the interpretive tradition of symbolic interactionism (Glaser & Strauss, 1967). Symbolic interactionism focuses on how people define events and realities and how they behave based on their beliefs and experiences (Eaves, 2001), whereas grounded theory requires that theory emerge from inductive discovery of systematically analyzed data. Therefore, the purpose of grounded theory is to develop a theory about dominant social processes through the discovery of theoretically complete explanations about particular phenomena. In grounded theory, systematic analysis of the data is a rigorous procedure that "offers qualitative researchers a set of clear guidelines from which to build explanatory frameworks that specify relationships among concepts" (Charmaz, 2006, p. 510). Asking questions and making comparisons are key procedures that inform and guide analysis and aid in theorizing. In grounded theory, research questions are flexible, open-ended, and sufficiently broad to enable a systematic inquiry to be conducted of all aspects of the phenomena in depth (Strauss & Corbin, 1998). The open-ended research question asked was "Tell me about the experience of being a breast cancer survivor." The researcher listened carefully to the ideas expressed by the participants and asked questions if necessary for clarification. Questions asked to prompt the conversation include the following.

- What thoughts come to mind when you think about your experience with breast cancer?
- Have you changed because of the experience of breast cancer?
- Is your life different in any way?
- How have you managed the experience?
- What lessons have you learned?

Sample

The purposive sample included 15 women who were diagnosed with early-stage breast cancer, were aged 18 years or older, spoke English, completed treatment (chemotherapy or radiation therapy) ranging from within one year to five years and beyond treatment, and who had no history of breast cancer recurrence or major comorbid health conditions. Participants were recruited through a LISTSERV announcement posted on the SHARE Web site (www.sharecancersupport.org), which offers Internet support for women diagnosed with breast cancer through discussion groups,

breast cancer information, and a telephone hotline for questions or support. Women interested in participation were given the e-mail and telephone contact information of the principal investigator. In addition, the research team conducted purposeful recruitment of women known to have been diagnosed and treated for breast cancer. Participants also referred women they knew by giving them the telephone number of the principal investigator or coinvestigators if they were interested in participating in the study. The sample size was not decided before the study began, but relied on theoretical sampling (sampling on the basis of theoretically relevant constructs) (Tavakol, Torabi, & Zeinaloo, 2006). As recommended by Strauss and Corbin (1998), enrollment of participants in a grounded theory study occurred until "theoretical saturation" occurred, meaning (a) no new or relevant data emerged regarding a category, (b) the category was well developed in terms of its properties and dimensions demonstrating variation, and (c) the relationships among categories were well established and validated (p. 212). Six participants were recruited from the SHARE Web site, four were identified as women with breast cancer by members of the research team, and five were referred by other participants in the study. When informed about the study, none of the potential participants declined participation nor withdrew from the study. All participants were from the tristate area of New York, New Jersey, or Connecticut.

Data Collection

New York University granted institutional review board approval for the current study. Individuals who were interested in participating were asked to contact the principal investigator by telephone to discuss the study's inclusion criteria. On agreement to participate, a date, time, and private location were set to conduct the interview. All participants requested to be interviewed in their homes. The principal investigator or coinvestigator obtained informed consent, indicating the voluntary nature of participation, ability to withdraw from the study at any time, and confidentiality of the interview data. Participants were informed that the interviews would last about 90 minutes and that a second interview might be requested to further elaborate on ideas from the first interview or to clarify ideas. The consent emphasized that although study participation had no expected risks, participants might experience a benefit by having opportunities to discuss their experience and perceptions. An additional benefit to participation may have included the recognition that participants were potentially helping future patients with breast cancer. In the event of any unexpected distress or concerns associated with participation in the study, a coinvestigator who also is a psychotherapist was available to provide emotional support or to make referrals to address ongoing psycho-

logical needs. Notably, none of the participants reported distress or requested additional consultation. Transcripts and tapes were accessible only to the research team and were kept in a locked file cabinet.

Data Analysis

Prior to data analysis, the principal investigator compared each audiotape to the typed transcript to ensure accuracy of transcription. The qualitative data analysis program NUD*IST (Non-numerical Unstructured Data Indexing, Searching and Theorizing) was used to assist in the examination of the data. Following the interviews, the researchers wrote field notes documenting their perceptions related to the interview, observations, hunches, and insights that were relevant to understanding the phenomena and theory development. As suggested by Chamberlain (2000), data collection and data analysis were fused deliberately and initial data analysis was used to shape continuing data collection. Constant comparative analysis combined an analytic procedure of constant comparison with an explicit coding procedure for generated data. The aim of that method was the generation of theoretical constructs that, along with substantive codes, categories, and their properties, formed a theory that encompassed and explained as much behavioral variation as possible (Hutchinson & Wilson, 2001).

To develop the theory that emerged from the data of this study, the researchers systematically read the transcripts and field notes line by line and dwelled with the data by listening to the tapes. Next, coding occurred at three levels. During level I coding, the researchers read the data line by line and identified code words known as substantive codes because they codify the substance of the data and use the words of participants. During level II coding, the researchers constantly compared new level I codes with previously identified codes and condensed them into broader categories. Each category then was compared to every other category to ensure they were mutually exclusive. Finally, during level III coding, the researchers collapsed level II codes to identify constructs, which led to the discovery of basic social science psychological processes. The goal in grounded theory is the discovery of a core variable, which illuminates the main theme and explicates the meaning of the verbatim data. Concept modification and integration occurred as researchers continued to analyze the data and moved from a descriptive to a theoretical level as they referred to their memos. Memos helped the researcher raise data to a conceptual level to develop the properties of each category and generate hypotheses about how the categories are related (Tavakol et al., 2006). Concurrently with data analysis, selective sampling of literature was conducted to learn what had been published about the emerging concepts.

Data Trustworthiness

All members of the research team verified that the four central criteria for grounded theory were met to ensure trustworthiness: (a) the theory fit the phenomenon, having been carefully derived from diverse data, and was faithful to the everyday reality of the study participants; (b) the theory was understandable and comprehensible to people being studied and others involved in the area (member checking); (c) the theory provided generality in that the data were comprehensive, the interpretation was broad and included extensive variation, and the theory was abstract enough to be applicable in a wide variety of contexts in the area of inquiry; and (d) the theory provided control by stating those conditions under which it applies, providing a basis for action (Strauss & Corbin, 1998). No threats to those criteria were encountered. Trustworthiness further was established through peer debriefing and review of the systematic processes of data collection and data analysis. Member checking in which the findings were shared with five participants also was conducted to ensure the accurate representation and interpretation of the data.

Results

Table 1 shows demographic and clinical data. Overall, the sample (N = 15) was Caucasian, middle to older age, married or in a committed relationship, a parent, and well educated, with full or part-time employment. Seven were diagnosed with stage II breast cancer without major comorbidities, although some had minor concurrent medical conditions. Most participants had a lumpectomy followed by chemotherapy, radiation therapy, or both.

The Process of Breast Cancer Survivorship

A substantive theory of breast cancer survivorship was understood through the shared thoughts and experiences of the study participants (see Figure 1). The participants described the experience of breast cancer as a transformational process as they moved from the acute phase of the illness through the immediate post-treatment phase and into the future. The experience was a journey, during which time they moved forward with life while being physically, emotionally, socially, and spiritually changed by the breast cancer experience. The perceptions and experiences of the participants revealed overall that the diagnosis of breast cancer was a turning point in life and the stimulus for change. That was followed by the recognition of breast cancer as now being a part of life, leading to the necessity of learning to live with breast cancer, and finally, creating a new life after breast cancer.

Although the literature discusses the concept of survivorship, the perceptions and experiences of par-

ticipants highlighted the discovery of a core variable, Reclaiming Life on One's Own Terms, which illuminated the main themes and meaning of the experience. Reclaiming Life captures the idea that participants were able to focus beyond illness, thoughts of death, and loss of life as they knew it to refocus on living life with new perspectives and in ways that promote physical,

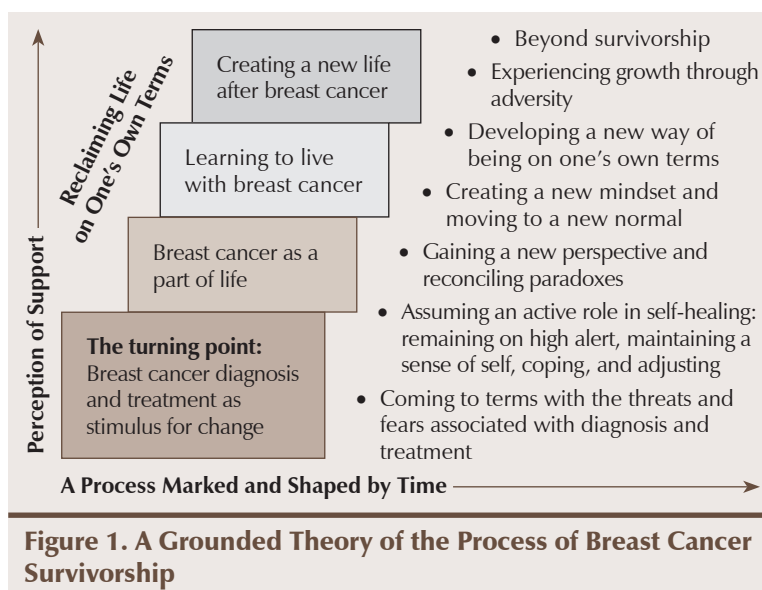
Table 1. Sample Characteristics

Characteristic	n
Age (years)	
18–29	1
30–39	—
40–49	3
50–59	7
60–69	4
Caucasian	15
Marital status	
Married	10
Committed relationship	2
Single	2
Widowed	1
Children	
None	6
Aged 1–20 years	5
Aged 20 years or older	4
Education	
High school	1
Associate degree	1
Bachelor's degree	2
Master's degree	8
Doctoral degree	3
Employment status	
Full-time	9
Part-time	3
Unemployed	1
Disability	1
Retired	1
Cancer stage	
Ductal carcinoma in situ	1
I	7
II	7
Primary surgical treatment	
Mastectomy	6
Lumpectomy	9
Adjuvant therapy	
Chemotherapy and radiation	6
Chemotherapy alone	4
Radiation alone	2
None	3
Hormonal therapy	
Yes	10
No	5
Years since completion of treatments	
1–5	6
6–10	5
11–15	3
16–20	1
Other current medical conditions?	
Yes	7
No	8
N = 15	

emotional, and spiritual well-being, on their own terms. Participants revealed that breast cancer survivorship is a process marked and shaped by time, the perception of support, and coming to terms with the trauma of a cancer diagnosis and the aftermath of treatment. The process of survivorship continues by assuming an active role in self-healing, gaining a new perspective and reconciling paradoxes, creating a new mindset and moving to a new normal, developing a new way of being in the world on one's own terms, and experiencing growth through adversity beyond survivorship.

A process marked and shaped by time: The post-treatment phase, known as survivorship, was identified by participants as a critical time point in which they faced the challenge of relegating experiences into two phases: before and after breast cancer. Life as they once knew it was "forever changed." Many experienced a "glimpse behind the curtain"—a realization of their mortality and vulnerability, which changed their previously held views of life and challenged them to rethink what and who was important as they moved forward with living. Phases of breast cancer survivorship beyond the treatment phase were marked in months and then years. That occurred first in three-month intervals with continual medical check-ups with physicians and the healthcare team, then in recognition of making the "one-year mark" where the experience is "still too fresh" but "the healing continues," followed by the five-year mark in which greater hope exists that cure has been achieved. Finally, beyond five years was a time when cancer had been relegated consciously to the past but a preconscious vigilance remained as "a wondering if cancer will lead to eventual death or whether death will be due to something else."

A process influenced by the perceptions of support: Participants also revealed that breast cancer survivorship involved a shared experience with others, including husbands, children, family, friends, women in the breast cancer community, other women, health professionals, and people with whom they work and interact. In conveying their personal journey, participants discussed their perceptions of support from others that either cushioned the many dimensions of pain or negatively influenced their recovery. Positive support was perceived when women experienced active presence of others, offering of supportive, loving gestures, acceptance, validation, positive reaction, demonstrations of strength (e.g., a shoulder to lean on), and the message that "we are in this together." However, negative support was perceived when others were unhelpful, expressed unwanted concern, abandoned the women physically or emotionally, ignored their fears and concerns, remained



silent as if nothing had happened, were unable to understand the grief associated with loss and illness, labeled or stigmatized them as "the one[s] with cancer," or were so emotionally needy themselves that the participant needed to shift her energies from her own healing to offer reassurance and direction to others. With positive support, many participants expressed a recommitment to the relationship, particularly with their husbands or significant others. With negative support, the participant reconsidered the value of the relationship and decided to "let go of toxic relationships," including separation or divorce from their husbands or significant others.

Coming to Terms With Threats and Fears Associated With Diagnosis and Treatment

From the time of diagnosis through the completion of treatment, participants expressed their sense of threat and fears of injury. Breast cancer was described as an injury that brought them back to previous physical injuries or life traumas. Having previously perceived themselves as healthy, that image was immediately challenged as they looked at their surgical scars or hairless heads, and their once "pink cheeks now [were] pale or marked by the lines of worry." Physically and emotionally, women were "knocked off their feet," "numbed by the blow," and "sick to death." Their threat to self also extended to threat to others as they feared breast cancer in their daughters or sisters, imagined leaving their husbands and children, and feared rejection by others, including the inability for single women to date and find a partner. On a deeper level, the treatment of breast cancer was marked by a "nagging fear of death." That fear was related not only to the process of dying or the state of being dead, but the figurative deaths of relinquishing their prior roles in the care of their families or at work. The figurative deaths came when they believed that they could no

longer look forward to the future because of its uncertainty, and in the “freshness” of their pain, they were unable to see beyond the current suffering from the disease and its treatment. The fear of death “invaded dreams—with screaming, anger, and rage” as they “desired to kill the messenger.” Some participants were now members of a club they did not want to join—the survivorship club—a term that was repulsive for some as it “forces you to acknowledge that you have a life-threatening illness” and are “forever different from everyone else.” However, the word carried a sense of hope for others. Each participant expressed in some way coming to terms with the threats and fears associated with the illness and injury and a need to find a way past it.

Assuming an Active Role in Self-Healing

During the first year after breast cancer treatment, participants described their active role in healing the self as they had to “come to grips” on many levels with their experience. Awareness of the need to heal was an ongoing process as women moved on with life and living. Participants described their active role of healing as remaining on high alert and maintaining a sense of self and coping, which involved denial, taking control, having a healthier lifestyle, protecting oneself, coping with physical and sexual changes, managing additional side effects or complications of treatment, and adjusting to breast cancer.

Remaining on high alert required physical and emotional energy for self-protection. Participants described “running to the doctor for every pain or ache or unusual feeling” and needing reassurance that the cancer had not advanced or recurred.

Maintaining a sense of self and coping, for some participants, involved the use of denial as a coping mechanism (i.e., pushing themselves to resume their roles as mothers, homemakers, or employees and act as if cancer had not affected them). That sometimes was fueled by family members who, although often being supportive and attentive during the acute phase, now were perceived as wanting to “move beyond the breast cancer experience,” leaving more than one participant feeling alone and isolated in their experience. Denial at some points also was a form of insulation from the threats of cancer and the threat to life as it was known previously. However, denial was just a “momentary reprieve” from reality as participants asked themselves, “What do I have to do to protect myself?” Participants understood that they had to take control by making decisions regarding their lives, which involved identifying and making choices. Sometimes the choice was not to allow bad thoughts, compartmentalizing the experience, projecting a sense of optimism and remaining positive to protect self and others, avoiding negative images, and “not listening to the horror stories,” while

“often comparing your situation to someone else’s and realizing that they have it far worse.” Taking control also involved either seeking information or consciously deciding “not to seek information but to rely on physicians to develop the best plan of care.”

In addition, maintaining a sense of self was expressed as participants realized they had to care for themselves and have a healthier lifestyle by eating right, exercising, reducing stress, and being aware of environmental pollutants that may have contributed to the cancer. Having a healthier lifestyle also involved health promotion and maintenance by “making sure you kept your appointments to the doctor and for tests” so that problems could be diagnosed early. That was a form of self-protection and often led to the decision to take tamoxifen or aromatase inhibitors, which limit the chance of recurrence. Beyond physical and emotional self-healing, spiritual healing involved hope, faith, and prayer so women could “make it through.”

Self-healing involved coping with physical changes such as lymphedema, alterations in body image (e.g., loss of a breast, scars, unevenness of breasts, weight gain), and neuropathic pain from chemotherapy, as well as changes in memory or concentration because of “chemo brain.” Participants described challenges to active healing in terms of coping with the side effects or complications of treatment, including breast pain, abdominal pain or tightness for those who had reconstruction, loss of sensation in the breast or abdomen, changes in temperature of the skin of the chest, cramping or numbness of the hands or feet because of chemotherapy, skin redness and burning because of radiation, loss of energy, and generalized anxiety. In addition, healing often involved coping with sexual changes, such as premature menopause with hot flashes, night sweats, irritability, and sometimes “the great disappointment of not being able to have children,” or coping with decreased libido, decreased vaginal lubrication, difficulty having orgasms, or painful intercourse. Coping not only entailed managing physical or sexual changes of oneself, but coping with the response of partners to those changes. In coping with sexual changes, women struggled and felt insufficiently counseled by healthcare practitioners.

Overall, self-healing necessitated adjusting to breast cancer. Although many of the physical effects of cancer and its treatment continued with lesser, the same, or greater intensity, self-healing required learning to adjust (i.e., doing everything one can to be healthy and stay healthy, as well as learning to accept sensations and trying not focus on the changes).

Gaining a New Perspective and Reconciling Paradoxes

In the process of self-healing and moving forward, participants described the need to find a new perspective

regarding their experience and reframe their meaning of survivorship. They spoke about the importance of going beyond the “why” (e.g., “Why me, what did I do, how could I have prevented this?”). That required not dwelling on or overanalyzing the event and was described by many as a “light-bulb moment,” “wake-up call,” “gift,” or “opportunity.” Many women expressed a sense of gratefulness, feeling lucky or fortunate to be living in a time when breast cancer no longer means certain death, and perceived an opportunity to “take stock of what you have” and “get on with life.” They expressed the importance of keeping “breast cancer in its proper place” and not succumbing to fear and limiting life, but rather “energizing life.”

Achieving a new perspective required reconciling paradoxes (see Figure 2). For those in the process of survivorship, choices are made as to which paradox dominates. Participants who are able to find a new perspective learn to live with uncertainty, view cancer in the relative present (something to watch for but in the past), do not consider cancer as being a part of them, see themselves not as victims but survivors, let go of fear, confront death, feel stronger, break boundaries, recognize that changes also have other causes, and become open in sharing their experience with others. In finding perspective and moving toward regaining normalcy, some women realized, “It is not my time to die—but my time to live.” Participants realized that a new mindset was being created that did not dismiss the experience of breast cancer, but required a new way of thinking about the experience and its impact on life in terms of relationships with oneself and others.

Creating a New Mindset and Moving to a New Normal

As participants moved further away from the immediate experience of breast cancer and its treatment over time, they realized “there was no turning back as life would never be the same.” In regaining a sense of normalcy, many said they wanted their old life back, being once again comfortable and familiar with their body, resuming roles, and feeling relaxed. However, they understood that a “new normal” had to be achieved and accepted. They realized that they had to “live in the present” and “capture the moment,” while recognizing that they were changed by the cancer experience. Breast cancer had to be “integrated into the story of life.” Participants also shared the need to “break out of your comfort zone” with new interests and new passions and accept that symptoms such as those of lymphedema and concerns about recurrence as part of the new normal could be “placed on the back burner and not always on the front burner of your mind.” They had to make choices about how to live life and

respond to the world. They learned to move forward despite fear and to increasingly manage uncertainty. As participants began to accept who they are, they also tried to make the experience worthwhile as they shared it with others. Some even showed their new breast to other women to let them see for themselves what was possible with today’s surgical procedures, and they often became advocates for others. In some ways, the experience helped them cope with other life tragedies (e.g., September 11) because if they had lived through one tragedy, they could live through another. With a new mindset, participants expressed the resultant new way of being in the world.

Developing a New Way of Being in the World on One’s Own Terms

Participants were changed from their former selves, reporting a new sense of who they were. As stated in their words, the experience gave them “permission to be myself,” “a new acknowledgement of my own needs with less self-sacrificing,” “feeling less self-conscious with less caring of what others think,” and a feeling of “reasserting oneself and feeling less restricted.” Women frequently described cancer as an opportunity. They portrayed themselves as less likely to behave in a way that was overwrought with emotion or overanalyzing situations. Likewise, they were “less willing to compromise,” “felt less obligated to agree,” and “no longer needing to be the ‘good girl.’” One participant stated, “With this came the ability to take greater risks and change from ‘what I have to do to what I want to do—living life on my own terms—reclaiming life for me!’” Many women said that it was time to “let go of toxic relationships,” “move away from individuals who drain your energy,” and “connect with those who help you live life fully.” In addition to self-improvement, women described greater empathy for others’ suffering and compassion for loss. Many participants felt the “need to give back” by helping others who were newly experiencing cancer and volunteering time in some way to those in need of support.

Experiencing Growth Through Adversity Beyond Survivorship

Growth was described as a process that has “no clear beginning and no ending.” Participants were “still alive and had not died.” They realized that cancer could return, and although they were afraid of reliving the experience, many noted that they had “faced death once and could do it again—this time with less fear.” The process of survivorship was transformational, as it built character and resulted in them “becoming a better person—easier to get along with, and more tolerant.” The experience also made them stronger, as breast cancer “produced a coat of armor” and led to the realization that “what doesn’t kill you makes you

Being a Victim of Cancer

- With a diagnosis of cancer, you are no longer free—the shadow of cancer is always with you.
- Breast cancer is like being in a minefield—you never know when you will become its victim.

Being a Survivor of Cancer

- I survive by compartmentalizing cancer—I know now that I can survive—I did it once—I can do it again if it recurs.
- Cancer knocked me off my feet—but I am now standing back up.
- I took a licking but I keep on ticking.
- I took life back into my control—I survived.
- My goal was to get healthy and stay healthy.
- It is important to be a survivor and not a victim.

Cancer as a Part of Me

- Cancer is a part of me—it is now a constant in my life.
- I will also view myself as having cancer. I am just waiting for it to reoccur.

Cancer Is Not Me

- I am not cancer. It is an event in my life but doesn't define me.
- The thought of cancer remains with me, but I put [it] in a smaller place in my life. It is not on the front burner of my brain.

Cancer as Present

- I am always worried that cancer will come back.
- You are always alarmed at every little change in your body.
- Life will never be the same again.
- Breast cancer is not in the past—I live with it every day.

Cancer as Past

- I did what I had to do to get through it and now I have moved on—it is in the past.
- You tell someone you had breast cancer and it's like . . . it's part of your history now . . . you had breast cancer and you're lucky to be alive—what do you care about anything else?
- Over time, cancer shifts from the forefront of your mind—it is back there but you realize you shouldn't worry about something you can't control.

Changes Are Caused by Cancer

- My body will never be the same—my breast is gone, my hair is different, I have gained weight, and I have all the menopausal side effects you get with chemotherapy.

Changes Are Not Caused by Cancer

- I am the same person I always was—many of the changes would have happened with age alone so I try to remember that—it is not always related to the cancer.

Concealing the Diagnosis

- I didn't want anyone to know I have cancer—I didn't want to be looked upon differently.
- I didn't want the big unveiling.
- I didn't want to tell people at work because I didn't want to be labeled as the “woman with breast cancer.”
- I was trying to protect others so I delayed in telling them—I kept it a secret.

Revealing the Diagnosis

- I realized that I needed transparency—you have to be open—you have to be real about what is going on in your life.
- It was such a relief when I told my family—because then I got so much support.
- I realized that if I revealed my diagnosis I could help others going through it.

Continuing Fear

- I wonder if I am ever going to feel normal again.
- I live with fear every day.
- I keep turning inward to understand why and what went wrong.

Letting Go of Fear

- You have to learn to let go of fear and put cancer in perspective and not let it consume you.
- I realize if I have overcome cancer, I am strong and can overcome many other things.

Creating Boundaries

- I needed to make my life circle smaller—stay safe within the limits of my family—in a cocoon.

Breaking Boundaries

- Breast cancer is a growing process—things don't upset you in the same way—you learn to let go of the people and relationships that bring you down—break out of old patterns and behaviors and create a new way of life.
- I am learning to be very selective in my life—I am not wasting my time with you if you drain me and am rethinking what is important.

Fear of Death

- I cried all the time that death was coming for me.

Confronting Death

- I took my life back—I am too stubborn to die—not now, I said.
- I have faced my mortality and I am no longer afraid of death.

Feeling Different

- I want my life back the way it was—life is very different now.

Not Feeling Different

- I refuse to give breast cancer the power—I am determined not to have my life be different.

Suffering From Uncertainty

- I was so distressed—with the diagnosis of cancer I was heading into the unknown—my life was on the line.
- At some points I felt paralyzed by uncertainty. I felt like I was going to the guillotine, I just didn't know when.

Living With Uncertainty

- I get information to deal with the uncertainty. There are no guarantees in life—you just have to accept that.
- I have learned to live with uncertainty. I take one day at a time—otherwise you could go crazy with the what-ifs.
- I think of uncertainty now as helpful—if there is no definite answer—it says that I will just deal with whatever comes along. It actually works to my advantage—using the notion of uncertainty in a different way.

Feeling Vulnerable

- Cancer makes us aware that we are vulnerable.
- When I go for breast studies, I am constantly reminded that I am vulnerable and in one day my life can change.
- I felt vulnerable—but I am a fighter.
- When you are first diagnosed you live in the present because you can't see a future.

Feeling Stronger

- I now take advantage of everything I can—breast cancer becomes a start to a new life—a life in which I participate fully.
- I have grown through this experience—I am not the same person—it has absolutely changed me and I am stronger.
- What is important is to learn from the experience to do something constructive with it—to help others get through it so that you are both stronger for it.
- It has really produced a coat of armor.

Figure 2. Paradoxical Narratives of Breast Cancer Survivors

stronger.” Participants described having an openness to living full with new interests, insights, and a greater sense of connection to self, others, and God. Breast cancer was “a doorway to humanity” as it created a “search for something bigger than yourself” and “offered a moment of grace.”

Discussion

Consistent with the findings of other researchers (Cooper, Loeb, & Smith, 2010; Meneses et al., 2007; National Cancer Institute, 2006; Rosedale, 2009; Rosedale & Fu, 2010), the current findings show that the experience of breast cancer survivorship is a process that is marked and shaped by time. Participants spoke of time before and after breast cancer. Time also was marked by months and years beyond treatment, first in three-month intervals that included visits to physicians to assess healing and monitor the effectiveness of surgery and adjuvant therapy, past the one-year mark of recovery, to the five-year mark when cure or at least long-term remission was likely.

The literature also suggested that cancer survivors move through three stages of illness (Bauer-Wu & Farran, 2005; Hewitt, Greenfield, & Stovall, 2006; National Cancer Institute, 2006; Pavia & Mason, 2004; Rosedale, 2009), which has been supported by the current study's findings. The first stage, known as the acute stage, begins with the diagnosis of cancer and continues to the completion of initial treatment, which is characterized by a survival focus and frequent interactions with the medical team. A sense of loss of control and disruption produces a focus on the immediate present. The second stage, termed the extended stage, is characterized by uncertainty with gratefulness for the success of the initial interventions, although residual sadness and continued fear regarding recurrence remain. While attempting to restore a sense of order to their lives, women experience confusion between present and future perspectives. Adding to the confusion is the need to resolve seemingly irreconcilable paradoxes and the often-felt social imperative described by Thomas-MacLean (2005) that women with breast cancer return to daily life looking and behaving as though nothing happened. The third stage, which involves the perception that one is a breast cancer survivor who has integrated the acute experience of the disease into her life and appreciates mortality, represents two perspectives: the need to be vigilant about health and recurrence, and the need to embrace experiences and important relationships. Occasional fears of recurrence persist, but for the most part, women believe they survived (Pavia & Mason, 2004).

The experience of breast cancer also is shaped by the positive support of others, including reassurance, love,

encouragement, and hopefulness, or negative support, including unwanted concern, a sense that others are not willing to hear concerns, or implicit or explicit encouragement to relegate the experience to the past and move on with life with a dismissal of feelings and issues; that finding also was confirmed by other investigators (Budin et al., 2008; Fu, Axelrod, & Haber, 2008; Rosedale, 2009). In the current study, participants emphasized the value of support of other women who walked them through the experience, prepared them in terms of what to expect, and were role models of survivorship. Despite existing physical changes and ongoing symptoms, women were embracing life and moving beyond. Consistent with the results of the current study, Pavia and Mason (2004) suggested that after medical treatments are completed and the immediate threat of cancer has passed, patients experience a broader realization of the situation and the need to find some sense of order that moves a person beyond illness to envision the future. Participants created a new mindset that included making choices about how to live their life. Pavia and Mason (2004) explained that, based on a phenomenologic study of breast cancer survivors, women express a need to stop denying important experiences and putting off for tomorrow what can be done today. Likewise, participants in the current study expressed the need to move beyond their comfort zone with new interests and passions. Nelson (1996) also found that women in the post-treatment phase of breast cancer sought to return to their normal lives; however, Sinding and Gray (2005) found that survivors are not “good as new but rather different and changed” (p. 152). That supports participants' experience of having a new normal.

Similar to the experiences of participants in the current study, Nelson (1996) found that the post-treatment phase included a period of learning new ways of being that included “living with uncertainty . . . as women chose how to redirect how they were going to live their lives” (p. 69). Women accomplished that by choosing other life paths in terms of work, relationships, and celebrating life's milestones. The research of Knobf (2007) reinforced that the breast cancer experience is an opportunity for growth and a new appreciation for life. As participants described growth through adversity, Bonanno (2004) also suggested that a person's response to traumatic events involves resilience, in which an individual moves to a healthier level of functioning and integrates the cancer experience as a part of their life experience. Thomas-MacLean (2005) reported that, although tension exists between the negative experience of breast cancer with changes to a woman's body as a constant reminder of illness, loss, and uncertainty, ongoing changes to embodiment also occur that incorporate growth and enlightenment.

Limitations

The current study was limited by the homogeneity of the sample and, therefore, the study should be replicated with more diverse populations to increase representativeness. Although a grounded theory approach was the appropriate method for addressing the aims of the current study, findings are limited to the women who participated and are not generalizable. Future research studies should build on the knowledge gained in this study.

Implications for Nursing

The findings of the current study suggest that the process of survivorship for women with breast cancer is an evolutionary journey that reflects short-term and long-term challenges. As women complete active treatment and transition into survivorship, they must move beyond the trauma of the diagnosis and treatment and the associated experience of suffering in all dimensions of life. The healing begins within the context of time and support. Women who move successfully through the process of survivorship begin to come to terms with physical, emotional, and spiritual trauma. However, women with breast cancer continue to suffer when caring has failed to take place and their suffering has been denied affirmation. When that happens, the patient is encouraged to give up her experiences and bury the significance of her illness in her life; as a result, the patient suffers from the struggle for wholeness and dignity (Arman et al., 2004). Patients protect themselves from disappointment by displaying false fronts of health, reducing their own needs and hiding signs of suffering. Healthcare professionals should be able to confront and validate suffering to support healing and refer patients to appropriate resources such as symptom management programs that address issues including lymphedema, neuropathy, and hot flashes (Fu & Rosedale, 2009); lifestyle change programs for nutrition, exercise, yoga, and other holistic strategies; and support groups and cognitive-behavioral approaches that emphasize a collaborative role between women and their providers that support women's active role in self-healing. In addition,

a cognitive-behavioral approach can be used to help women identify thoughts about survivorship and assist them in the process of gaining new perspectives and reconciling the paradoxes they describe. All healthcare professionals should remember that self-healing is a long-term challenge that appears to go through distinct phases but needs to be individualized for the treatment for each woman.

Models of care in which nurses and nurse practitioners can facilitate bridging the gap between acute cancer care and long-term survivorship care are needed. A nurse-led model that assists women in taking control, facilitating self-help (i.e., connecting women with other breast cancer survivors), and self-care while providing surveillance is indicated by the study findings. Periodic assessment of quality of life is further recommended during primary care visits, as it provides an additional opportunity for identification of a change in health status.

This grounded theory study has identified the relationships among critical concepts in the process of survivorship from breast cancer. Time, support, coming to terms with the trauma, active self-healing, new perspectives, the creation of new mindsets, and acceptance of a new normal allow women to develop a new way of being in the world and provide an opportunity for growth. The relationship among those concepts can be tested through future research studies and serve as the empirical foundation for interventions that support the process of breast cancer survivorship.

Deborah Witt Sherman, PhD, APRN, ANP-BC, ACHPN, FAAN, is a professor and codirector of the Center for Excellence in Palliative Care Research in the School of Nursing at the University of Maryland in Baltimore; Mary Rosedale, PhD, PMHNP-BC, NEA-BC, is an assistant professor of nursing in the College of Nursing at New York University and an advanced practice nurse in the Department of Psychiatry at NYU Langone Medical Center, both in New York; and Judith Haber, PhD, APRN, CS, FAAN, is the Ursula Springer Leadership Professor and associate dean for Graduate Programs in the College of Nursing at New York University. No financial relationships to disclose. Sherman can be reached at sherman@son.umaryland.edu, with copy to editor at ONFEditor@ons.org. (Submitted April 2011. Accepted for publication June 29, 2011.)

Digital Object Identifier: 10.1188/12.ONF.E258-E268

References

- American Cancer Society. (2012). Breast cancer. Retrieved from <http://www.cancer.org/cancer/breastcancer>
- Aranda, S., Schofield, P., Weih, L., Milne, D., Faulken, R., & Voudouris, N. (2005). Mapping quality of life and unmet needs of urban women with metastatic breast cancer. *European Journal of Cancer Care*, 14, 211–222. doi:10.1111/j.1365-2354.2005.00541.x
- Arman, M., Rehnsfeldt, A., Lindholm, L., Hamrin, E., & Eriksson, K. (2004). Suffering related to health care: A study of breast cancer patients' experiences. *International Journal of Nursing Practice*, 10, 248–256. doi:10.1111/j.1440-172x.2004.00491.x
- Bauer-Wu, S., & Farran, C.J. (2005). Meaning in life and psycho-spiritual functioning: A comparison of breast cancer survivors and healthy women. *Journal of Holistic Nursing*, 23, 172–190. doi:10.1177/0898010105275927
- Boehmke, M. (2004). Measurement of symptom distress in women with early-stage breast cancer. *Cancer Nursing*, 27, 144–152. doi:10.1097/00002820-200403000-00008
- Bonanno, G.A. (2004). Loss, trauma, and human resilience. *American Psychologist*, 59, 20–28. doi:10.1037/0003-066X.59.1.20
- Budin, W.C., Hoskins, C.N., Haber, J., Sherman, D.W., Maislin, G.,

- Cater, J.R., . . . Shulka, S. (2008). Breast cancer: Education, counseling, and adjustment among patients and partners: A randomized clinical trial. *Journal of Nursing Research*, 57, 199–213. doi:10.1097/01.NNR.0000319496.67369.37
- Carlsson, M., Arman, M., Backman, M., & Hamrin, E. (2005). Coping in women with breast cancer in complementary and conventional care over 5 years measured by the Mental Adjustment to Cancer Scale. *Journal of Alternative and Complementary Medicine*, 11, 441–447. doi:10.1089/acm.2005.11.441
- Cartwright-Alcares, F. (2004). *Information needs of women with breast cancer in recovery*. Retrieved from ProQuest Dissertations and Theses database (AAT No. 3155727).
- Chamberlain, K. (2000). Methodolatry and qualitative health research. *Journal of Health Psychology*, 5, 285–296. doi:10.1177/135910530000500306
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage.
- Cooper, J.M., Loeb, S.J., & Smith, C.A. (2010). The primary care nurse practitioner and cancer survivorship care. *Journal of the American Academy of Nurse Practitioners*, 22, 394–402. doi:10.1111/j.1745-7599.2010.00528.x
- Dirksen, S. (2000). Predicting well-being among breast cancer survivors. *Journal of Advanced Nursing*, 32, 937–943. doi:10.1046/j.1365-2648.2000.01559.x
- Eaves, Y.D. (2001). A synthesis technique for grounded theory data analysis. *Journal of Advanced Nursing*, 335, 654–663. doi:10.1046/j.1365-2648.2001.01897.x
- Fu, M.R., Axelrod, D., & Haber, J. (2008). Breast cancer-related lymphedema: Information, symptoms, and risk-reduction behaviors. *Journal of Nursing Scholarship*, 40, 341–348.
- Fu, M.R., & Rosedale, M. (2009). Breast cancer survivors' experiences of lymphedema-related symptoms. *Journal of Pain and Symptom Management*, 38, 849–859. doi:10.1016/j.jpainsymman.2009.04.030
- Ganz, P.A., Desmond, K.A., Leedham, B., Rowland, J.H., Meyerowitz, B.E., & Belin, T.R. (2002). Quality of life in long-term, disease-free survivors of breast cancer: A follow-up study. *Journal of the National Cancer Institute*, 94, 39–49. doi:10.1093/jnci/94.1.39
- Gil, K.M., Mishel, M.H., Belyea, M., Germino, B., Germino, L.S., Porter, L., . . . Stewart, J. (2004). Triggers of uncertainty about recurrence and long-term treatment side effects in older African American and Caucasian breast cancer survivors. *Oncology Nursing Forum*, 31, 633–639. doi:10.1188/04.ONF.633-639
- Glaser, B.G., & Strauss, A.L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Aldine.
- Gluck, J. (2007, May 28). The survivor monologues. *New York Magazine*, 30–45, 105–108.
- Golden-Kreutz, D., & Andersen, B. (2004). Depressive symptoms after breast cancer surgery: Relationships with global, cancer-related and life event stress. *Psycho-Oncology*, 13, 211–220. doi:10.1002/pon.736
- Health Care for Women International. (2001). Why grounded theory and women's health? *Health Care for Women International*, 22, 1–3. doi:10.1080/073993301300003027
- Hewitt, M., Greenfield, S., & Stovall, E. (2006). *From cancer patient to cancer survivor: Lost in transition*. Washington, DC: National Academies Press.
- Hoybye, M.T., Johansen, C., & Tjornhoj-Thomsen, T. (2005). Online interaction. Effects of storytelling in an Internet breast cancer support group. *Psycho-Oncology*, 14, 211–220. doi:10.1002/pon.837
- Hutchinson, S., & Wilson, S. (2001). Grounded theory: The method. In P.L. Munhall (Ed.), *Nursing research: A qualitative perspective* (3rd ed., pp. 209–218). Sudbury, MA: Jones and Bartlett.
- Knobf, M.T. (2002). Carrying on: The experience of premature menopause in women with early stage breast cancer. *Nursing Research*, 51, 9–17. doi:10.1097/00006199-200201000-00003
- Knobf, M.T. (2007). Psychosocial responses in breast cancer survivors. *Seminars in Oncology Nursing*, 23, 71–83. doi:10.1016/j.soncn.2006.11.009
- Landmark, B.T., Strandmark, M., & Wahl, A.K. (2001). Living with newly diagnosed breast cancer—The meaning of existential issues. *Cancer Nursing*, 24, 220–226.
- Meneses, K., McNeese, P., Loerzel, V., Su, X., Zhang, Y., & Hassey, L. (2007). Transition from treatment to survivorship: Effects of a psychoeducational intervention on quality of life in breast cancer survivors. *Oncology Nursing Forum*, 34, 1007–1016. doi:10.1188/07.ONF.1007-1016
- Mols, F., Vingerhoets, A.J., Coebergh, J.W., & van de Poll-Franse, L.V. (2005). Quality of life among long-term breast cancer survivors: A systematic review. *European Journal of Cancer*, 41, 2613–2619. doi:10.1016/j.ejca.2005.05.017
- National Cancer Institute. (2006). Estimated US cancer prevalence counts: Definitions. Retrieved from <http://dcccps.nci.nih.gov/ocs/definitions.html>
- Nelson, J. (1996). Struggling to gain meaning: Living with the uncertainty of breast cancer. *Advances in Nursing Science*, 18, 59–72.
- Pavia, T., & Mason, M. (2004). The reflexive relationship between consumer behavior and adaptive coping. *Journal of Consumer Research*, 31, 441–454. doi:10.1086/422121
- Rosedale, M. (2009). The survivor-loneliness of women following breast cancer. *Oncology Nursing Forum*, 36, 175–183. doi:10.1188/09.ONF.175-183
- Rosedale, M., & Fu, M. (2010). Confronting the unexpected: Temporal, situational, and attributive dimensions of distressing symptom experience for breast cancer survivors [Online exclusive]. *Oncology Nursing Forum*, 37, E28–E33. doi:10.1188/10.ONF.E28-E33
- Samarel, N., Tulman, L., & Fawcett, J. (2002). Effects of two types of social support and education on adaptation to early-stage breast cancer. *Research in Nursing and Health*, 25, 459–470.
- Sammarco, A. (2001). Perceived social support, uncertainty, and quality of life of younger breast cancer survivors. *Cancer Nursing*, 24, 212–219. doi:10.1097/00002820-200106000-00007
- Schmidt, J.E., & Andrykowski, M.A. (2004). The role of social and dispositional variables associated with emotional processing in adjustment to breast cancer: An Internet-based study. *Health Psychology*, 23, 259–266. doi:10.1037/0278-6133.23.3.259
- Sinding, C., & Gray, R. (2005). Active aging—Spunky survivorship? Discourses and experiences of the years beyond breast cancer. *Journal of Aging Studies*, 19, 147–161. doi:10.1016/j.jaging.2004.05.001
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research. Grounded theory procedures and techniques*. Newbury Park, CA: Sage.
- Tavakol, M., Torabi, S., & Zeinaloo, A.A. (2006). Grounded theory in medical education research. *Medical Education Online*, 11(30), 1–6.
- Thomas-MacLean, R. (2005). Beyond dichotomies of health and illness: Life after breast cancer. *Nursing Inquiry*, 12, 200–209. doi:10.1111/j.1440-1800.2005.00268.x
- Tomich, P.L., & Helgeson, V.S. (2002). Five years later: A cross sectional comparison of breast cancer survivors with healthy women. *Psycho-Oncology*, 11, 154–169. doi:10.1002/pon.570
- Trunzo, J.J., & Pinto, B.M. (2003). Social support as a mediator of optimism and distress in breast cancer survivors. *Journal of Consulting and Clinical Psychology*, 71, 805–811. doi:10.1037/0022-006X.71.4.805
- Tulman, L., & Fawcett, J. (2002). A framework for studying functional status after diagnosis of breast cancer. *Cancer Nursing*, 13, 95–99.
- Vivar, C., & McQueen, A. (2005). Informational and emotional needs of long-term survivors of breast cancer. *Journal of Advanced Nursing*, 51, 520–528. doi:10.1111/j.1365-2648.2005.03524.x