Negotiating Emotional Order: A Grounded Theory of Breast Cancer Survivors

Jennifer A. Klimek Yingling, Utica College

Abstract

In this article, classic grounded theory captures the processes of 12 women who had completed initial treatment for breast cancer. The qualitative data analysis reveals the basic social process of negotiating emotional order that describe how breast cancer survivors perceive their illness and decide to take action. From the data, five stages of the process of negotiating emotional order emerge: 1) Losing Life Order, 2) Assisted Life Order, 3) Transforming 4) Accepting, and 5) Creating Emotional Order. This study may help healthcare providers who care for breast cancer survivors understand the depth of perpetual emotional impact that breast cancer survivors endure. This study will potentially serve as a path for future research and aid in the understanding of the psychological impact that breast cancer has upon survivors.

Keywords: breast cancer, survivor, chemotherapy, emotional order

What Sparked This Research

I cared for a patient who I had gotten to know as her child often visited the emergency department due to hemophilia. She was a pleasure to work with, strong, level headed, and upbeat. On this particular day she was the patient. Her complaint was simple: a cough and she clearly wasn't herself emotionally. I was surprised to discover, when I took her past medical history, that she was a breast cancer survivor. After I discussed her chest x-ray results I sensed she was still upset and filled with uncertainty. Then the lightbulb went on. I asked her directly if she was concerned if the cancer was recurring. She said yes and her tears flowed. I do believe if I had not dug a little deeper into her emotional state she would have left the emergency department with much of the same emotional duress that she initially had. This interaction sparked my research as it was clear that breast cancer survivors endure a process after treatment ends. For these survivors the treatment is over but the emotional aspect of breast cancer is not. It also became evident to me that healthcare providers need to know more about this process on order to be able to treat patients holistically.

Negotiating Emotional Order: A Grounded Theory of Breast Cancer Survivors

Breast cancer is the most prevalent cancer found in women worldwide (American Cancer Society [ACS], 2016; Ferlay et al., 2104). In the United States, it is estimated that 3.5 million women have been diagnosed with breast cancer; 245,000 will be newly
diagnosed; and, approximately 40,000 women will succumb to breast cancer annually (ACS, 2016; Breastcancer.org, 2016). Early detection and improved treatment is credited to the rising population of women who are breast cancer survivors (Howlader et al., 2015; McCloskey, Lee, & Steinburg, 2011). Concerns about the psychosocial ramifications of chronic illness have a long history. The Institute of Medicine (2009), American Cancer Society (2015), and the American Society of Clinical Oncology (2015) resonate concern about psychosocial hindrances regarding cancer patients, citing them as a critical area needing improvement within the nation's health care system.

The literature suggests breast cancer survivors endure psychological stressors after the completion of treatment including the following: loneliness (Marroquin, Czamanski-Cohen, Weihs, & Stanton, 2016; Rosedale, 2009), anxiety and depression (Walker, Szanton, & Wenzel, 2015), uncertainty (Dawson, Madsen, & Dains, 2016; Mishel et al., 2005), and fear of recurrence (McGinty, Small, Laronga, & Jacobsen, 2016). The phenomenon of breast cancer survivorship has been identified with qualitative methods, yet is lacking explanatory theory (Allen, Savadatti & Levy, 2009; Pelusi, 1997). Qualitative analysis uses inductive rather than deductive investigation of a clinical phenomenon for capturing themes and patterns within subjective perceptions to generate an interpretive account to inform clinical understanding. Inductive methods are used by the researchers to discover and generate theory (Artinian, Giske, & Cone, 2009; Glaser, 2008). Therefore, grounded theory was chosen to study the process of survivorship in women who have completed treatment for breast cancer.

Method

A Glaserian grounded theory design was chosen to explore the process of transition survivorship in women who have completed treatment for breast cancer. Grounded theory allows the researcher to explore a phenomenon and build theory from concepts going through processes and transitions (Glaser & Strauss, 1967; Glaser, 2008). The ACS defines cancer survivor as "anyone with a history of cancer, from the time of diagnosis through the remainder of their life" (ACS, 2016, p. 3). This definition was used for inclusion criteria for this project. Prior to commencement of the research, approval from the university's institutional review board was secured. A purposive sample was sought and participants were self-identified breast cancer survivors in a suburban community in Northeast United States. A presentation was made at a local breast cancer survivorship group. Flyers were posted in community centers, libraries, and public places including areas that reach numerous individuals. Based on these recruitment efforts, 12 women were interviewed during a four-month period.

Data Collection

All participants received written and verbal information about the study and gave informed consent. Data were collected by completing the following: a demographic data form, approximately one-hour individual in-depth interviews, observational notes, and field
notes. All of the data was handled in a confidential manner. Each interview session lasted approximately one hour in length. Broad open-ended questions were used to stimulate discussion of thoughts and feelings about extended survivorship. Focused questions and prompts were used to elicit more specific information from participants about their actions to attain and maintain psychosocial health after the completion of breast cancer treatment. The focus questions also elicited information about processes used to modify and maneuver through adversities after completion of treatment. Each participant was asked to describe situations when she knew something had changed in her health and psychosocial status after the completion of treatment for breast cancer. Participants were asked to answer the questions until they felt they had no information to add to the topic.

Data Analysis

Data analysis took a Glaserian approach in which data collection, analysis, and memoing were ongoing and concurrent throughout the research. Each interview was digitally taped and transcribed. Atlas ti software was used as a depository to code, store, and memo during analysis. Data was coded line by line to fracture the data into nouns formed from a verb or gerund. The interviews were re-coded on three different occasions. After the initial interview was coded, the second interview was coded in a similar fashion and the data were examined for common constructs that were clustered. Subsequent interviews were open-coded and compared with ideas and relationships described in the researcher’s memos. As the categories unfolded, some categories were re-coded or combined with other categories. At the conclusion of the last interview, all codes were sorted to certify fit. Once a core variable or category was identified, coding became selective. The researcher continued the interviews and coding until saturation of the core variable was achieved. On saturation, theoretical coding was used to intersect categories within the data. Exploration of the literature for substantive codes that were significant was conducted each day. Extensive memo taking was used via manual notes and also as freehand drawn visuals created by the researcher to capture the researcher’s mind set.

Trustworthiness

For the purpose of this paper, a conglomerate of trustworthiness criteria grounded from the recommendations of Glaser (1978, 1998, 2001) was employed. The researcher who conducted this study had scant exposure to extended breast cancer survivors in her personal and professional realm. Techniques to establish credibility included prolonged engagement and peer debriefing. Theoretical sampling and constant comparison took place when data, analytic categories, interpretations, and conclusions were discussed and tested with study participants throughout the interview process. Prolonged engagement developed rapport and participant trust. To address transferability, the following groups of data was included in an audit trail: 1) raw data, 2) data reduction and analysis notes, data reconstruction and synthesis products, 3) process notes, 4) materials related to intentions and dispositions, and 5) preliminary development information. The researcher kept a reflexive journal to record methodological decisions and the rationale for the decisions, the planning and management of the study, and reflection upon the researcher’s own principles, feelings, and interests. Lastly, external audits were conducted by several researchers not involved with the research process on several occasions.
The Theory of Negotiating Emotional Order

The main concern of the women is the struggle for emotional order. The meaning inherent in the basic social process of Negotiating Emotional Order is that women who have been diagnosed with breast cancer strive for emotional order by negotiating control of the negative feeling of threats to their mortality and to live their daily lives. The process described in the theory of Negotiating Emotional Order changes as the situation of the breast cancer survivors’ changes. As time passes, the women move from discovering an abnormality to a time after treatment ends. This process is dynamic and perpetual in nature because the threat of cancer recurrence remains until the end of the breast cancer survivor’s life. For some women, negotiating emotional order is achieved even when the cancer recurs or metastasizes.

The participants’ actions and decisions illuminate the perpetual struggle to negotiate emotional order. For some, order is compartmentalizing negative thoughts and emotions that they could not control. For others, they accept the fact that they cannot control cancer but project order onto other aspects of their lives. The struggle for emotional order is present from the time the survivor found the abnormality into long-term survivorship and at times is cyclic. Five stages of the process of negotiating emotional order emerges from the data: 1) Losing Life Order, 2) Assisted Life Order, 3) Transforming, 4) Accepting, and 5) Creating Emotional Order.

Losing Life Order

During this time period, the realization of the threat of breast cancer disrupts emotional order with intense fear and uncertainty of the future. The breast cancer survivor often makes decisions and acts on her instincts to placate the immediacy that she feels prior to starting treatment, often seeks information from the Internet, popular literature, media and from others who have experienced breast cancer. Unfortunately, their need for immediacy is often not met by the health care community, so they take matters into their own hands and act.

Many of the participants voice that this time period is difficult, as they have multifaceted family roles as wives, mothers, and children of parents of their own causing additional emotional turmoil. The participants continue or attempt to continue with their family roles by working, caring for children, and maintaining their households. The breast cancer survivors voice that they don’t have time to let cancer get in the way emotionally as they are too busy with family and work responsibilities. The participants speak of emotional duress when they see their families react to their illness and chose to protect their families by concealing their emotions. One participant talked about why she concealed her emotions: "The emotional impact it had on my family was horrible . . . I felt like I had to be strong for them . . . I would not show any emotions about being sick."

Losing order encompasses two properties of disorder: losing emotional order and losing physical order. Upon discovering an abnormality, and then confirming breast cancer, the breast cancer survivors report loss of control of their bodies, which causes emotional
duress. This stage marked the survivors’ first sense that cancer cannot be controlled. Loss of emotional order is represented by feelings of sadness, anger, immediacy, loneliness, fear, and uncertainty. This stage is hallmarked by emotional chaos and decision making. Approaches the women use in this stage are: taking matters into own hands and concealing to maintain family order.

**Assisted Life Order**

Surprisingly, although treatment is a physically draining endeavor, the breast cancer survivors voice that it is a time of respite when they focus on physical well-being rather than the emotional disruption that is occurring. During this phase, the women are often consumed with treatments of surgery, chemotherapy, and/or radiation. The participants state they feel proactive and protected while under the frequent care of health care providers. This participant’s narrative exemplifies the feeling of being assisted emotionally and physically by health care providers: "While you're getting chemotherapy, you think you're doing something to kill off any additional cancer that the surgery didn't get. You have certain protection."

The breast cancer survivors verbalize feeling lonely, despite having much social and family support, and purposely seek out other women who endured breast cancer for emotional support. Breast cancer survivors seek emotional support from formal and informal support persons. The participants also discuss a phenomenon where other breast cancer survivors would approach them after hearing about their diagnosis and come to their assistance to provide support. The importance of this camaraderie is evident in this narrative: "I didn't know people that have been through this...people came out of the woodwork. People that I had known that I didn't know that had cancer who shared their stories with me." Some of the breast cancer survivors express the need to have a connection with someone who has experienced breast cancer. Some women seek formal support groups for this need and continue to use them after treatment is completed.

The second stage of negotiating emotional order is assisted life order that occurs when the breast cancer survivor enters treatment and focuses all of her energy into physical well-being. At the same time, survivors entrust their life order into the hands of health care providers and rely on social support to carry them through the time that they are in treatment. During this time, the breast cancer survivor keeps physically and emotionally occupied with the routine of appointments and treatment. During this time, the women feel treatment is a sanctuary and they express that during this time they feel lonely in their current experience. During the second period, they engage with others with formal training or personal experience with breast cancer to establish emotional order.

**Transforming**

At this stage of the process, the breast cancer survivors report a cutting point or a crossroads and make a change in thought process. They are autonomously responsible for their physical and emotional well-being. This autonomy is a sharp contrast to their behavior while in treatment, where they live day to day and do not think about the future. Once treatments end, survivors must take the wheel and navigate into their life and the future. It does appear that this cutting point is an emotionally charged timeframe: the temporary
sanctuary of treatment ends and many survivors feel the need to take subjective responsibility of their emotional order. The survivors speak about the need to reach inward to claim emotional order to live their lives beyond breast cancer.

During this stage, the threat changes from the fear of the diagnosis of cancer to the fear of cancer. The fear of cancer can be recurrence of breast cancer, occurrence of a new cancer, and/or cancer metastasis. The process of beginning to move on from the emotional effects of the diagnosis of breast cancer begins shortly after the end of treatment. Fear is initially intense then becomes manageable over time for many. Several women note the recurrent fear abates somewhat after the first year and even more after five years. The fear of recurrence also can return many years after the completion of treatment. This dread is especially true if the breast cancer survivor discovers new symptoms or abnormalities that lead her to believe the cancer has returned. Often waiting for the results of diagnostics causes extreme anxiety and fear of recurrence.

The interviewed participants ranged from three months to twenty-four years post treatment. Despite the variation of time since the ending of treatment, all of the participants discussed levels of fear of recurrence. Often, the fear of recurrence affects their daily lives initially until they set cancer apart from living their present life. Several of the participants state it is not so much an inherent process rather an active decision to take control of their feelings of fear and move forward. In this stage, the turning point is the active decision to leave breast cancer in the past and focus on the present and future. Another participant, who is thirteen years post treatment, discussed this decision: "I told myself, I have to make a move here. You can curl up in a ball and die or I can move on. I started moving on."

When the breast cancer survivors leave treatment, they are at a crossroad in which feelings of loss and confusion are produced. After adjuvant treatment ends, the breast cancer survivors must remap their lives and begin to strive for a new normalcy in their lives. The threat at this stage changes from the diagnosis of cancer and is replaced with the fear of recurrence. The breast cancer survivors often revisit their own mortality during this time and these feelings can cause loss of emotional order. During this time the breast cancer survivor transforms, remapping their life course and also moving on from fear.

Accepting

Uncertainty of the future also causes emotional distress for breast cancer survivors. The reality that none can control their own mortality or cancer, is an aspect of the emotional trajectory that the breast cancer survivors struggle with initially. Once breast cancer survivors make this realization, they can then subjectively gain order of their emotions. This action is autonomous as no one else but the breast cancer survivor can complete this task. One participant spoke about this decision: "There are things that I can change and there are things that I am powerless over. It’s distinguishing and I do have control over what I’m thinking."

Although the breast cancer survivor attempts to control her emotions, she often will come to the realization that she can keep her emotions in order rather than control them so that she can move on in her life and get serenity with the past diagnosis of breast cancer. Several of the participants state the turning point occurs when they realize they cannot
control cancer or their feelings, and thus accept order versus control. As the threat of recurrence is no longer an issue, they accept their mortality and are living in the present day. A participant reflection on this concept: "We'll all go some day. It's just my time might come sooner than expected. A part of life."

Feelings of emotional loss of control can be triggered by reminders after treatment ends. Reminders include physical reminders, body image reminders, diagnostics, and society cancer awareness. Although gaining realization of their own mortality, living with reminders forces the breast cancer survivors to cope on a daily basis with the fear of recurrence as they are reminded by physical and cognitive aftermath of breast cancer. Additionally, diagnostics and health care visits can elicit feelings of fear. Breast cancer survivors also voice that breast cancer or cancer awareness activities in the community and media also trigger feelings of fear. The impact of reminders is showcased by one participant’s remarks: "I worry about it all the time. Every ache and pain I have. When my bones hurt I wonder if it is bone cancer. Every time I have to have a mammogram, I pray it’s not there."

**Creating Emotional Order**

Inherently, human beings have emotions. One of these emotions is fear in response to a threat. As the threat of cancer recurrence has a perpetual quality in women who have been diagnosed with breast cancer, the emotional aspect of cancer recurrence is long-standing. Since she cannot fully control her emotions, the breast cancer survivor will compartmentalize negative feelings of uncertainty and fear to achieve emotional order. To protect themselves emotionally, several of the participants speak about triaging these emotions to the back of their heads and putting these feelings away. One participant illustrates this behavior: "It’s probably because I pushed it to the back of my head because I don’t want to deal with those emotions."

Once the breast cancer survivor accepts the fact that there are aspects of her life she can control and there are aspects over which she has no power, she will begin to create emotional order. Having control over actions and or parts of her life allows the breast cancer survivor to have emotional order. During times of emotional distress, they also increase their attempts to distract themselves from their emotions. This increase in activity temporarily increase with times of stress. Often, after the breast cancer survivor feels well, she redefines the actions in which she participates. Survivors express themselves by participating in activities that they enjoy or want to experience but did not have the courage to do so prior to diagnosis. Breast cancer survivors also talk about controlling their family roles and home environment. The breast cancer survivor might demonstrate control by creating a household routine or enumerating familial activities. Distracting self with other aspects of life also is a way that breast cancer survivors create emotional order. By immersing themselves back into their daily routines of work, marital, household, and family roles, survivors limit the amount of time they have available to think about the fear of recurrence, which is similar to using activity to occupy time during the assisted life order stage.
Social comparison through self-evaluations is another way that these participants achieve emotional order. Breast cancer survivors use social comparison as a method to create emotional order by viewing their experience as better than others who experienced poor outcomes. As a defense mechanism, if the breast cancer survivor views her experience as positive then she reaffirms she is a survivor. Social comparison is evident almost unanimously in the data. Participants speak often of reflecting on the experience they endured and feel lucky. While exploring this code the researcher asked the participants what they meant by luck or being lucky. Consistently the participants talk about luck as comparing outcomes as better or worse. For example, when asked what she meant by having better luck, a participant replied: "Well I was thinking someone maybe had the same surgery as me, did better than me." Here is an example of a breast cancer survivor socially comparing her experience as worse than another person’s experience.

In addition to evaluating the actual treatment outcomes and evaluating the way that they physically dealt with treatment, the breast cancer survivors also evaluate the entire experience of breast cancer by reflection. The ability to reflect onto the past experience to find benefits and assign positive outcomes related to the cancer allow the survivor to make sense of the experience and create emotional order. In many ways, the survivors feel everything that they endured was worth what they became. Many reflect back and feel they gained knowledge of self-meaning knowing their bodies and emotions and realized they have abilities to endure adversity that they did not know before the experience of breast cancer. The breast cancer survivors reflect back in awe of the emotional stamina that they had during adversity and were proud of their accomplishments. One participant states: "It is amazing. Yeah if someone had told me I could write a book, become a massage therapist and learn the body the way I have. I would have said no way."

"I feel like I know these people. You have been through what they have been through." This participant’s narrative sums up the transparent common bond the participants feel with other cancer survivors. To create emotional order, the breast cancer survivors help others as a way to help themselves emotionally. Planned helpfulness allows the breast cancer survivor to create emotional order by gaining satisfaction through assisting others. Often breast cancer survivors employ ambiguousness until they are ready to disclose their survivorship status. This opacity allows them to experience empowerment and also allows them life choices–a common theme throughout the interviews. Breast cancer survivors plan and decide how they would help others; many are grateful for the acquaintance disclosure and guidance they receive early in their disease trajectory and want to pay forward some type of comfort to others who are enduring cancer.

Once survivors accept the fact that they cannot control their mortality and cancer, the breast cancer survivor creates social order to protect herself emotionally. Breast cancer survivors are acutely aware that their actions do not guarantee that cancer will not return, but in this stage they want to maintain a status of being physically and emotionally healthy. One participant communicates: "What work do I need to do. I am a survivor and want to be a survivor for a long time." Although reminders often trigger fear, the survivors often use methods to create emotional order, to find balance and not allow feelings of fear to overcome them. Breast cancer survivors protect themselves by controlling their actions,
Creating Emotional Order allows breast cancer survivors to transcend the fear of recurrence by controlling their actions, compartmentalizing negative feelings, and using social comparison and planned helpfulness. Although they cannot control their emotions or control cancer, they can control the way they react to emotions and take control of their life actions. Many of the participants shelve their negative emotions in order not to let the psychological aspect of breast cancer interfere in their daily lives. The participants show evidence that the survivors can regress between stages of this theory, but after their initial passage through the stages progress forward quickly and resiliently.

**Limitations**

There are several limitations in this research. First, the researcher attempted to recruit a variety of participants from diverse social and demographic backgrounds through flyers posted in public places. Despite this attempt to obtain a diverse population, all the participants are White and hold high school education or equivalency and most of the sample had three or more years of college education. Most of the participants are married or partnered. Economic and insurance status information is not included in the demographic data. Expanding the demographic sample might have allowed modifiability of the theory to explore additional relationships between these variables and the process of survivorship.

Finally, grounded theory analyses are population specific. This research represents the primary step in theory development. The aim of grounded theory construction is to hone and develop a theory in the attempt to produce formal theory. Testing the applicability of this theory may be appropriate in other populations who face severe illnesses, for example individuals as they face the aging process, individuals who are facing a terminal illness, veterans returning from war diagnosed with post-traumatic stress disorder, men facing prostate cancer, and/or women facing infertility.

**Discussion**

The aim of this study is to contribute to the knowledge of breast cancer survivorship. This research contributes to the literature as a lack of holistic research exists on the process of extended survivorship that involve the fragments of the process of survivorship. Breast cancer is a significant and prominent healthcare challenge for many women in the United States. Negotiating emotional order is identified as the core category allowing women to survive emotionally after completing treatment for breast cancer. Five stages were identified including the following: Losing Life Order, Assisted Life Order, Transforming, Accepting, and Creating Emotional Order. The grounded theory of negotiating order integrates and highlights the importance of recognizing emotional health in breast cancer survivors.

This research challenges a staple in cancer survivorship literature that is reported by Mullan (1985) in several ways. First, in the current study, breast cancer survivors described
the process of survivorship beginning before diagnosis with the discovery of an abnormality. This variation in the genesis of process of survivorship is different from Mullan’s (1985) model in which the process of survivorship is said to begin with diagnosis. Second, a new stage that represented transitional survivorship or Stage III: Transforming is described in the current study as the period immediately following the completion of treatment. Third, Mullan (1985) described extended survivorship as ending once the survivor enters remission. Although most breast cancer survivors interviewed for this study entered remission, several experienced recurrences or metastatic breast cancer so Mullan’s model excluded the process that these individuals endured.

Lastly, in this study extended survivorship appeared to be a continuous state rather than a conduit to permanent survivorship as Mullan (1985) described in his model. Mullan (1985) stated permanent cancer survivorship begins once the person is considered cancer free and can successfully return to their normal physical and emotional abilities prior to the cancer diagnosis. The survivors in this study describe extended survivorship to have a perpetual nature rather than being permanently cured physically or emotionally. They also challenge the fact they would return to "normal." One of the participants states, "It was a rough road. Trying to figure out who I was, where I belong. Because they say your life goes back to normal, there is no normalcy. I don't feel I am normal today." This idea is significant as many breast cancer survivors may feel the need to feel "normal" due to the extensive publication of Mullan’s (1985) model. The use of Mullan’s (1985) model by many credible cancer authorities may prove to be confusing and frustrating to breast cancer survivors who lack the feeling of normalcy after treatment is completed and into extended survivorship.

The theory of Negotiating Emotional Order supports several existing theories that describe how individuals handle severe illnesses beyond cancer. This work complements several authors who described survivorship beyond the biomedical model that psychosocial and environmental factors influence (Collins, 1995; Festinger, 1954; Folkman & Greer, 2000; Taylor, 1983; Walker, Jackson, & Littlejohn, 2004).

The construct of control can be found in the literature in multiple patient populations including breast cancer (Warren, 2010), cardiac disease (Svansdotti et al., 2012), patients with obsessive compulsive disorder (Kang, Namkoong, Yoo, Jhung, & Kim, 2012), diabetes (Hughes, Berg, & Wiebe, 2012), and sexual assault (Frazier, Morlensen, & Steward, 2005). In this study, loss of emotional control is important, as it serves as a catalyst shaping the decisions and actions of the participants. Additionally, controlling actions were used later by the participants as a means to cope, thus creating emotional order. This theme is analogous with Folkman’s (1984) description of control as dynamic coping mechanism with shifting appraisal as result of a stressful encounter or environment.

Benefit finding and planned helpfulness that are reported are consistent with Taylor’s (1983) proposed theory of cognitive adaptation in response to threatening events as both are displays of a search for meaning in the experience and attempts of mastery to restore self-esteem. It may also be noted that Taylor (1983) linked an individual’s sense of control to positive cognitive adaptation. Lastly, social comparison is evident in this group. This observation echoes Festinger’s (1954) work hypothesizing that social comparison is done to
promote self-normalcy. Social comparison in this population is a mechanism to negotiate emotional order by improving the survivors’ positive perception of their situation and is consistent with the work Collins (1995) reported.

**Implications for Practice**

This research affords a glimpse into the experience of survivorship from the perspective of women who have completed treatment for breast cancer and how they survived emotionally from the detection of an abnormality into extended survivorship. This work aids in the development of a broad understanding of the processes that individuals endure when faced with a serious health status alteration. This information might aid health care providers to understand the immediacy that breast cancer survivors experience during the disease trajectory and the concept that the fear of recurrence can last perpetually and be an issue that is important to survivors until the end of their lives.

A lesson that can be taken away from this work is that women are continuously attempting to create emotional order and this clearly indicates they need support to continue well after treatment ends. In terms of theory, the identification of the process used by breast cancer survivors to negotiate emotional order may be helpful for health care providers who care for, educate, and design nursing interventions for this population. This study of survivorship after breast cancer establishes the beginning process of generating a formal grounded theory on survivorship that could, through further theoretical sampling, be extended beyond this patient population. Building on existing theory, this qualitative data analysis may help explain the mechanisms used by populations who have experienced a life-threatening illness personally or while supporting a loved one.

**Acknowledgements**

I would like to thank the breast cancer survivors who shared their personal survivorship journey for this research. I also thank Dr. Elise Lev, Dr. Karen D’Alonzo, Dr. Claudia Beckman, Dr. Louise Dean Kelly and Naomi Tobes for their encouragement and invaluable contributions to this work.

**Declaration of Conflicting Interests**

The author declares no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

**Funding**

This research is supported the Rita C. Koph Memorial Research Award generously given by the Foundation of New York State Nurses, Cathryne A. Welch Center for Nursing Research

**References**

32


This study explored breast cancer survivors’ perspectives regarding their experiences of the survivorship continuum from diagnosis through 30 months post-treatment. The sample included women (N = 379) with newly-diagnosed breast cancer undergoing treatment at a Midwestern university-affiliated cancer center. Survivors expressed a need to advance their health care literacy in order to share ownership of breast cancer and lymphedema treatment decisions. Since breast cancer is an immune-mediated disease, long-term survivorship planning should address psychosocial factors that influence the long-term psychological distress associated with immune dysfunction. Breast cancer survivorship needs to be fully understood by nurses and health care providers (HCP) in order to obtain optimal health outcomes for this ever growing population. Method: Classic grounded theory was used in this study to explore the process of transitional survivorship from the prospective of women who had completed initial treatment for breast cancer. Approval by the Institutional Board of Research at Rutgers University and Faxton St. Luke’s Healthcare was obtained prior to the commencement of the research. Twelve women were interviewed. Participants were attempting to bring the psychological aspect of having breast cancer into a state of order by negotiating control with cancer, themselves and external factors.