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**Women's Experiences During the  
First Year Following Diagnosis of  
Breast Cancer**

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**ABSTRACT**

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This phenomenological study examined what it was like for a sample of twenty women to live with breast cancer during the first year following diagnosis. Audiotaped interviews were conducted with the women and data were conceptualized by the researcher as representing three overlapping phases of the experience: The diagnostic phase, the treatment phase, and the post-treatment phase. Findings: The diagnostic phase revealed a period of "impact" in which six themes were identified: 1) receiving the news, 2) fear, 3) being strong, 4) persistent thoughts, 5) multiple stressors, and 6) spiritual awareness. The treatment phase, one of "re-traumatization," was characterized by four themes: 1) making choices, 2) pain and suffering, 3) determination to fight, and, 4) support from others. Three themes depicted the post-treatment phase of

“resolution/healing”: 1) fear of recurrence, 2) behavioral changes, and 3) personal growth.

The central meaning statement that best described the experience of women living with breast cancer during the first year following diagnosis is that the experience is a gradual, private, social, and spiritual process in which an initial trauma takes place, re-traumatization occurs during the course of treatment, and all efforts are directed at resolution/healing. This study has implications for practitioners who treat women diagnosed with breast cancer.

***Keywords: breast cancer, trauma, psychosocial, spirituality***

## **Background**

Breast cancer is a leading cause of cancer death in women in the United States, second only to lung cancer. The American Cancer Society predicts that in the year 2001, 192,200 new cases of invasive breast cancer will be diagnosed in women in the United States (US) and approximately 40,200 deaths will occur from the disease.<sup>1</sup> In addition, 46,400 new cases of *in situ* breast cancer are expected to occur, 88% of which will be ductal carcinoma *in situ* (DCIS), the most common form of noninvasive breast cancer. The good news is that at this stage the

<sup>1</sup>American Cancer Society (2001). *Cancer Facts and Figures 2001*, 10-11.

cancer has not yet spread into breast tissue and nearly 100% of women diagnosed can be cured with simple lumpectomy, radiation, and Tamoxifen®.

Mammography screening is directly responsible for the increase in detection of DCIS as well as infiltrating or invasive ductal carcinoma (IDC), a more serious form of the disease.<sup>2</sup> However, declines in breast cancer mortality rates are attributed to regular mammography screening.<sup>3</sup> As numbers of positive screenings and more effective treatments become available, more women are living longer with breast cancer. Concern is raised for the psychological, as well as the physical well-being and quality of life of those women at diagnosis, during treatment, and beyond.

<sup>2</sup>American Cancer Society (2001) *Breast cancer what is it?* [On-line] Available: [www3.cancer.org/cancerinfo/main\\_cont.asp](http://www3.cancer.org/cancerinfo/main_cont.asp)

<sup>3</sup>ibid.

<sup>4</sup>McGee, R., Williams, S., & Elwood, M. (1996). Editorial: Are life events related to the onset of breast cancer? *Psychological Medicine*, 26, 441-447.

<sup>5</sup>Roberts, F.D., Newcomb, P.A., Trentham-Dietz, A. Storer. B.E. (1996). Self-reported stress and risk of breast cancer. *Cancer*, 77(6), 1089-93.

<sup>6</sup>Lillberg, K., Verkasalo, P.K., Kaprio, J., TeppoHelenius, H. & Koskenvuo, M. (2001). Stress of daily activities and risk of breast cancer: a prospective cohort study in England. *International Journal of Cancer*, 91(6), 888-893.

<sup>7</sup>Jacobs, J.R. & Bovasso, G.B.

The association between cancer incidence and psychosocial stress has long been debated.<sup>4-9</sup> Meanwhile, numerous studies are currently underway to examine the role of stressors in the development of cancer. The processes of psychological adjustment to breast cancer are known to include intrusive thoughts, avoidance, anxiety, depression, and impairment in personal and work relationships.<sup>10-14</sup> Studies of women's quality of life in the aftermath of diagnosis and treatment also support the importance of the

(2000). Early and chronic stress and their relation to breast cancer. *Psychological Medicine*, 30(3), 669-678.

<sup>8</sup> Spiegel, D. & Kato, P.M. (1996). Psychosocial influences on cancer incidence and progression. *Harvard Review Psychiatry*, 4(1), 10-26.

<sup>9</sup> Geyer, S. (2000). The role of social and psychosocial factors in the development and course of cancer. *Wien Klin Wochenschr*, 112(23), 986-994.

<sup>10</sup> Baider, L., & De-Nour, A.K. (1997). Psychological distress and intrusive thoughts in cancer patients. *Journal of Nervous and Mental Disorders*, 185, 346-348.

<sup>11</sup> Carter, B.J. (1997). Women's experiences of lymphedema. *Oncology Nursing Forum*, 24(5), 875-882.

<sup>12</sup> Epping-Jordan, J.E., Compas, B.E., Osowiecki, D.M., Oppedisano, G., Gerhardt, C., Primo, K., & Krag, D.N. (1999). Psychological adjustment in breast cancer: Processes of emotional distress. *Health Psychology*, 18(4), 315-326.

<sup>13</sup> Vickberg, S.M., Bovbjerg, D., DuHamel, K.N., Currie, V. & Redd, W.H. (2000) Intrusive thoughts and psychological distress among breast cancer survivors: Global meaning as a Possible Protective Factor. *Behavioral Medicine*, 25, 152-159.

<sup>14</sup> Primo, K., Compas, B.E., Oppedisano, G., Howell, D.C., Epping-Jordan, J.E., & Krag, D.N. (2000). Intrusive thoughts and avoidance in breast cancer: Individual differences and associations with psychological distress. *Psychology and Health*, 14(6), 1141-1153.

<sup>15</sup> Longman, A.J., Braden, C.J., & Mishel, M.H. (1996) Side-effects burden in women with breast cancer. *Cancer Practice*, 4(5), 274-280.

<sup>16</sup> Ferrell, B.R., Grant, M., Funk, B., Garcia, N.,

psychological impact of cancer. Longman, Braden, & Mishel<sup>15</sup> found that quality of life during cancer treatment was negatively affected and associated with side-effects burden. Ferrell et al.<sup>16</sup> conceptualized breast cancer quality of life in four domains (e.g. physical, psychological, social, and spiritual), and reported that women experienced the most distress in the psychological domain.

Otis-Green, S. & Schaffner, M.L. (1996). Quality of life in breast cancer. *Cancer Practice*, 4(6), 331-340.

<sup>17</sup> Bolger, N., Foster, M., Vinokur, A.D., & Ng, R. (1996). Close relationships and adjustment to a life crisis: The case of breast cancer. *Journal of Personality and Social Psychology*, 70(20), 283-294.

<sup>18</sup> Gall, T., Miquez-de-Renart, R., & Boonstra, B. (2000). Religious resources in long-term adjustment to cancer. *Journal of Psychosocial Oncology*, 18(2), 21-37.

<sup>19</sup> Street, R.L. & Voigt, B. (1997). Patient participation in deciding breast cancer treatment and subsequent quality of life. *Medical Decision Making*, 17(3), 298-306.

<sup>20</sup> Stanton, A.L., Danoff-Burg, S., Camerob, C.L., Bishop, M., Collins, C.A., Kirk, S.B., Sworowski, L.A., & Twillman, R. (2000). Emotionally expressive coping predicts psychological and physical adjustment to breast cancer. *Journal of Consulting and Clinical Psychology*, 68(5), 875-882.

<sup>21</sup> *ibid.*

<sup>22</sup> Cowley, L., Heyman, B., Stanton, N. & Milner, S.J. (2000). How women receiving adjuvant chemotherapy for breast cancer cope with their treatment: A risk management perspective. *Journal of Advanced Nursing*, 31(2), 314-321.

<sup>23</sup> Street, 1997

Mediating factors (factors which influence outcomes positively or negatively and have repercussions relevant to meaning of the cancer experience) influence quality of life outcomes.<sup>17-20</sup> Specifically, these factors are differences in coping styles, participation in decision making, social support, and spirituality and/or religious participation. An emotionally expressive coping style was positively correlated with health status and hope and negatively correlated with psychological distress and number of physician visits. The reverse was true for women using avoidant coping styles.<sup>21</sup> A significant number of women undergoing adjuvant chemotherapy cope with the associated physical and psychological distress by actively attempting to keep their routines and attitudes as normal as possible.<sup>22</sup>

Street and Voight<sup>23</sup> found that quality of life was higher for women who perceived greater responsibility and choice for treatment decisions

than for those who perceived limited input or control over these decisions. There is some evidence that global meaning (sense that one's life has purpose and order) is a protective factor against psychological distress.<sup>24</sup>

<sup>24</sup> ibid

Social support is reported to be useful in helping people manage stressful events.<sup>25,26</sup> However, Bolger and colleagues<sup>27</sup> argue that the presence of social support does not alleviate patients' distress or promote recovery, nor does involvement with well-meaning relatives who have been affected with breast cancer.<sup>28</sup>

<sup>25</sup>Lugton, J. (1977). Health visitor support for patients with breast cancer-2. *Nursing Standard*, 11(35), 34-38.

<sup>26</sup>Courtens, A.M., Stevens, F.C., Crebolder, H.F., & Philipsen, H. (1996). Longitudinal study on quality of life and social support in cancer patients. *Cancer Nursing*, 19(3), 162-169.

<sup>27</sup>Bolger, 1996

<sup>28</sup>Ibid.

Spirituality is an important aspect of cancer care.<sup>29-31</sup> Fernsler, Klemm, and Miller<sup>32</sup> investigated the relationship between spiritual well being and the demands of illness imposed by a cancer diagnosis. The authors concluded that subjects who reported higher levels of spiritual well being experienced significantly lower demands of illness related to physical symptoms, monitoring symptoms, and treatment issues.

<sup>29</sup>Cotton, S.P., Levine, E.G., Fitzpatrick, C.M., Dold, K.H. & Targ, E. (1999). Exploring the relationships among spiritual well-being, quality of life, and psychological adjustment in women with breast cancer. *Psycho-oncology*, 8, 429-438.

<sup>30</sup>Mytko, J.J. & Knight, S.J. (1999). Body, mind and spirit: Towards the integration of religiosity and spirituality in cancer quality of life research. *Psycho-oncology*, 8, 439-450.

<sup>31</sup>Feher, S. & Maly, R.C. (1999). Coping with breast cancer in later life: The role of religious faith. *Psycho-oncology*, 8, 408-416.

<sup>32</sup>Fernsler, J.I., Klemm, P., & Miller, M.A. (1999). Spiritual well-being and demands of illness in people with colorectal cancer. *Cancer Nursing*, 22(2), 134-140.

<sup>33</sup>Pascrreta, J. (1997). Depressive phenomena, physical symptom distress, and

Pascrreta<sup>33</sup> reported that, although slightly less

functional status among women with breast cancer. *Nursing Research* (4), 214-220.

<sup>34</sup> Watson, M. Haviland, J.S., Greer, S., Davidson, J., & Bliss, J.M. (1999). Influence of psychological response on survival in breast cancer: A population-based cohort study. *Lancet*, 354, 1331-1336.

<sup>35</sup>Ferrell, 1996

<sup>36</sup>Brady, M.J., Cella, D.F., Mo, F., Bonomi, A.E., Tulskey, D.S., Lloyd, S.R., Deasy, S., Cobleigh, M., & Shimoto, G. (1997). Reliability and Validity

than the national norm, 9% of her sample ( $n=79$ ) met criteria for major depressive disorder or dysthymia and 24% had elevated depressive symptoms. These symptoms resulted in physical symptom distress and impaired functioning. Those women who achieved high scores on hopelessness and helplessness scales and on depression instruments had poorer patient outcomes and a significantly reduced chance of survival.<sup>34</sup>

Early detection and improved treatment is expected to reduce mortality in women with breast cancer. However, more women are living longer with the disease and must cope with the resultant psychosocial stress.

Most studies of the psychological effects of breast cancer have been quantitative and correlational, studying various aspects of the disease, e.g. coping, decision-making, social support, and spirituality. However, these studies do not capture the essence or the uniqueness of the breast cancer experience lived by each woman. Instruments designed for all cancer populations or for patients with chronic illness in general are frequently used in data collection.<sup>35</sup> The FACT-B,<sup>36</sup> a quality of life scale specifically designed for breast cancer patients, has recently been

of the Functional Assessment of Cancer Therapy-Breast quality-of-life instrument. *Journal of Clinical Oncology*. 15, 974-986.

introduced. However, it is not designed to capture the individual lived-experience of the woman with breast cancer. The phenomenological method used in this study was selected to illuminate factors that are absent in the existing literature and provide a clear sense of what the experience of breast cancer is like for each individual participant. The purpose of this study was to determine the meaning of the breast cancer experience to women living with the illness.

## Methods

Phenomenology has been described as a philosophy, an approach, and a method that aims to describe experience as it is lived.<sup>37</sup> In keeping with the two descriptive levels of the Giorgi<sup>38</sup> method of empirical phenomenological research, the original data were comprised of naïve descriptions obtained through open-ended questions and dialogue (Level I). The method entails asking the research question, “What was it like for you to be diagnosed with breast cancer?” and other appropriate questions in order to glean the meaning of the experience for the individual. The descriptions provided by the participant are the basis for a structural reflective analysis that depicts the essence of the experience (Level II).<sup>39</sup>

<sup>37</sup>Oiler C. (1982). The phenomenological approach in nursing research. *Nursing Research*, 31(3), 178-181.

<sup>38</sup>Giorgi A. (1985). *Phenomenology and psychological research*. Pittsburgh: Duquesne University Press.

<sup>39</sup>Moustakas, C. (1994). *Phenomenological Research Methods*. Thousand

*Sample.* Twenty women diagnosed with breast cancer comprised the sample for this study. Although this was a relatively large number for a phenomenological study, saturation (redundancy in data collection) was not achieved until the 20<sup>th</sup> interview. Eleven women were patients from a local cancer center in a Southeast region of the United States. The remaining participants were nominated by people who knew someone who had recently been diagnosed with breast cancer. The type of breast cancer, the location, and the severity of the disease varied for each woman. Approximately half of the women had found lumps while doing breast self-exam (BSE) and the remainder were diagnosed following detection of suspicious areas on mammograms. One woman had been diagnosed with breast cancer ten years prior, had a mastectomy, and then was diagnosed with cancer in the other breast. The treatments received by these women were diverse, ranging from simple lumpectomy to mastectomy. Some received radiation and/or chemotherapy and some were taking Tamoxifen®.

Participants ranged in age from 30 to 56 years. Eighteen were over the age of 50. Fifteen women were employed in professional occupations, three as non-professionals, and two were housewives.

Three women were African American; the rest were Caucasian. All had some type of health care coverage. Three were divorced, one was widowed, and the rest were married. They met sample criteria of having been diagnosed with breast cancer during the previous 12 months and of consenting to audiotaping of responses to an open-ended interview. Respondents were given a brief letter describing the purpose of the study, assurances regarding the confidential nature of the data and information regarding their right to withdraw from the study any time until the data were analyzed.

*Data Collection.* The interview began with a central question: What was the experience of breast cancer like for you? As interviews progressed, participant statements provoked seven common questions:

- 1) What were your thoughts and feelings when you first learned you had cancer?
- 2) What are they now?
- 3) Whom did you confide in first?
- 4) Who is your primary support person?
- 5) What effect has the illness had on your family as you cope with your illness?
- 6) What difficulties did you encounter in seeking treatment? and,
- 7) What kinds of things do you do to take care of yourself now that you did not do before?

Open-ended questions facilitated obtaining naïve descriptions, the process of dialogue, and helping participants describe lived experience.<sup>40</sup>

<sup>40</sup>ibid.

<sup>41</sup>Lincoln, Y. S. & Guba, E.G. (1985). *Naturalistic Inquiry*. Newbury Park: Sage.

According to Lincoln and Guba,<sup>41</sup> an unstructured interview in a non-standardized format is useful to avoid seeking normative responses. A priori researcher notions were bracketed in order to hold in abeyance presuppositions regarding participants' experiences.

Audiotaped interviews were conducted at a mutually convenient location. Many occurred at the cancer center where the woman was being treated or followed; some were conducted in the researcher's office. Interviews usually lasted one hour. Unclear data or meanings from verbatim audiotaped transcriptions were taken back to the participant for clarification when needed.

*Plan for Data Analysis.* The procedure for data analysis followed the method proposed by Giorgi.<sup>42</sup> The entire transcript was read in order to obtain a sense of the whole. The researcher then re-read the entire document again in order to isolate specific meaning units, while concentrating on the phenomenon under question. The researcher systematically

<sup>42</sup>Giorgi, 1985

eliminated redundancies, clarified meaning units, and related meaning units to each other and to the sense of the whole. The desired end product was a narrative description or central meaning statement that captures the essence of the experience for the participant and directly conveys the psychological insight contained in the interview.

Threats to trustworthiness in this project were handled through consideration of “credibility,” “transferability,” “dependability,” and “confirmability” as described by Lincoln and Guba.<sup>43</sup> Low inference descriptors, participant review of findings, and confirmation of findings by a peer who is skilled in the phenomenological method were additional techniques used to ensure trustworthiness. Low inference descriptors entailed the use of numerous verbatim accounts of informants’ descriptions in the phenomenological writing. Participant review of findings consisted of participant clarification of researcher perceptions of interview content.

<sup>43</sup>Lincoln, 1985

## **Results**

The meaning of living with a diagnosis of breast cancer is that it is *an experience that is a gradual, private, social, and spiritual process in which initial trauma takes place,*

*re-traumatization occurs, and all efforts are directed at resolution/healing.* Data analysis revealed that participants seemed to encounter three overlapping phases of the experience of living with breast cancer during the first year following diagnosis. The first phase (diagnostic phase) was conceptualized by the researcher as a period of “impact.” The second phase (treatment phase) as “resilience,” and the third (post-treatment phase) as “resolution/healing.” Phases were conceptualized after interviews and during data analysis for the convenience of organization and management of voluminous amounts of qualitative data. It is important to note that a significant overlap of themes occurred between phases, e.g. spirituality and fear. However, certain characteristics were predominant in a designated phase.

*The Diagnostic Phase (Impact of Diagnosis).*

The diagnostic phase of the experience was conceptualized as a period of “impact.” Six themes were descriptive of this period: 1) receiving the news, 2) fear, 3) being strong, 4) persistent thoughts, 5) multiple stressors, and 6) spiritual awareness.

*Receiving the News.* Shock, disbelief, and an initial “shutting down” characterized *receiving the news*, for a majority of participants.

Statements such as "I absolutely could not believe it; it floored me" and "by the time I got home I started crying, I was dry heaving and couldn't catch my breath" depicted clearly the impact that a positive breast cancer diagnosis had on many of the women. Even those women who suspected that the lump they had discovered or the shadow that had been seen on mammogram would turn out to be cancerous were not spared these feelings.

Participants received the news in a variety of ways. Some women were notified by phone by their physicians, some were told by well-meaning husbands who had kept positive biopsy results from their wives, and some were informed by surgeons during office visits. However, two participants had been told by their physicians that "it's nothing to worry about, you're too young, at your age this doesn't happen" only to end up with a positive breast cancer diagnosis later on. Ironically, some reported thinking that they were "safe" because they had no family history of breast cancer. Finding out that they had cancer meant that their previous assumptions were not valid and they were not "safe." A sense of vulnerability was evident under this category. It did not matter how the news was delivered. "Shutting down" was a mechanism for figuring out what was going on.

*Fear.* Initial fears experienced by the women included fears of death, surgery, and the treatment process. The women with children worried about what would happen if they were not alive to raise their children. One respondent stated,

*“Death popped in my mind, scared [me], and I began to cry; I began to think about my kids. Them being as young as they are and not having momma there.”*

Some individuals disavowed being afraid, stating that they had faith that “everything would be all right.” However, there was a sense that an adjustment had been made in initial thinking. Cancer changed their lives; adjustments were compulsory.

*Being Strong.* Women felt the need to “be strong” for family members and friends which meant that they were often deprived of the luxury of freely expressing emotion. Many cited assuming the role of comforter in order to keep spouses and children from “falling apart.”

One woman stated, “As long as I was there and doing everything, things were okay.” Another stated, “I felt like I needed to hold it together for my family.” Still another stated:

*“I tried not to do it (cry) in front of my family. I felt that it would just devastate*

*them. I tried to be strong...I never broke down in front of my mother because I could tell it was pretty hard for her. I tried to put up a pretty strong front. The situation was stressful enough and I didn't want them to see my suffering and make it that much worse for the people around me."*

*Persistent Thoughts.* Thoughts about the possibility of losing a breast, the stress of prescribed treatments, an uncertain future, and possible death were uppermost in the minds of the majority of the women and invaded daytime as well as nighttime awareness. Immersion in the breast cancer experience meant not being able to attend to usual activities of daily living. One participant stated:

*"I woke up at 3 in the morning, my heart was racing, my blood pressure was high. It was scary. I went to the emergency room but everything was fine. I think it was just an anxiety attack."*

*Multiple Stressors.* The majority of women cited experiencing multiple stressors in their daily lives prior to and concurrent with the cancer diagnosis. Some were caregivers to aging or ill parents, most had children, some had recently moved to their current locations, some had changed jobs, and one had had breast cancer previously. Having breast cancer meant that life had changed but still goes on.

*Spiritual Awareness.* Without exception, the women in this study recognized an increase in spiritual presence in their lives. Learning that they might die meant that they felt drawn to reevaluate their relationships with God and recognized that they needed something more powerful than themselves to see them through. They had faith that God would take care of them, and hope for a long and happy future. The following statements, by different participants, depicted the concept of spiritual awareness.

*“I prayed to God, and broke down, and asked him to carry me through this because I couldn't do it on my own.”*

*“It is tough to go through chemo. Just put God first. Sometimes it feels like He is far away, but, that is when He is carrying us. God didn't say our life would be easy. I believe it was John 16:33. It said, ‘We will have trials and tribulations but have good cheer because He has overcome them all.’ That let me know that He is still in the healing business. I believe wholeheartedly that He healed me and it (cancer) won't return.”*

*The Treatment Phase (Being Re-traumatized).*

The treatment phase, one of re-traumatization, was characterized by four themes: 1) making choices, 2) pain and suffering, 3) determination

to fight, and 4) support from others.

*Making Choices.* The majority of participants made choices regarding the type of surgery they would undergo and whether they would have radiation and/or chemotherapy. Access to care was not a problem for them. They listened to their physicians, sought second opinions, read whatever they could find related to breast cancer, and searched the Web for information that would help them make their decisions. Having cancer meant that they had to make choices. They were unwilling to adopt a “wait and see” attitude and were highly proactive in seeking treatment.

Regardless of the choice, having breast cancer meant that women had to choose for themselves. Some did exactly what their physicians told them to do. Others refused radiation, chemotherapy, or Tamoxifen®, stating that they knew intuitively that the cancer was gone. Concern for physical attractiveness was a key factor for two women in determining the type of treatment that they would undergo. One woman refused radiation stating that she did not want “red skin or a hard breast.” Another declined a course of Tamoxifen® fearing that she would gain weight. Although variability in decision-making existed, each woman took some sort of action.

*Pain and suffering.* Most of the women in this study suffered physical and emotional pain and discomfort proportional to stage at diagnosis, type of surgical procedure, and need for chemotherapy. Being in pain meant inability to accomplish usual tasks, self-absorption, and a resulting decrease in the capacity to focus on the needs of others. Those who were diagnosed early and who had radiation without chemotherapy seemed to exhibit more peace of mind and confidence in their prognoses. Although all of the women reported emotional pain and suffering, those who were diagnosed later with more invasive disease experienced the added discomfort of the nausea, vomiting, weight loss, and hair loss that were side effects of chemotherapy. Those who had undergone mastectomy exhibited more hopelessness and despair. Statements such as "I felt my world had come to an end," "I cried for days and weeks," and "I still have moments of despair" clearly depicted these concepts.

*Determination to fight.* All of the women in this study were determined to fight their cancers. Fighting meant taking control of the illness by following physician's recommendations for treatment, keeping their appointments, and engaging in appropriate follow-up. However, two

individuals “fought” using unconventional methods such as dietary supplements and vitamins. One woman who expressed a common sentiment stated: “I felt that most likely I would survive and I could beat this.”

*Support from others.* All of the women, whether married, widowed, or divorced, reported having good support systems. “My major support person was my husband because I could go to him and I could break down. He would lift me back up.” Several women stated that their husbands assured them that “We’ll go through this together.” They also derived significant amounts of support from the physicians, nurses, and technicians who treated them, as shown by frequent comments about the kindness, caring, and thoughtfulness of staff at their treatment facilities. Participants also cited support from their children, parents, and co-workers. Being supported meant not having to carry a horrendous burden alone.

*Post-treatment Phase (Progress Towards Resolution/Healing).* The post-treatment phase was depicted by a continuing process of *resolution/healing*: The major themes depicted in this phase included: 1) fear of recurrence,

2) behavioral changes, and 3) personal growth.

*Fear of Recurrence.* In spite of expressions of faith and hope, the women in this study described fearing that their cancers would return. All admitted to occasional thoughts about “what if the cancer returns?”

*Behavioral Changes.* Many women cited behavioral changes directed at promoting or preserving health. Having cancer meant trying to forestall further problems by engaging in regular exercise, making conscious efforts to eat healthfully and taking more time to spend with family in relaxing activities. An occasional participant cited that she had made no changes in her activities.

*Personal Growth.* The majority of women in this study felt that they had grown personally from the cancer experience. They were more patient with others, kinder, and more appreciative of “the little things in life.” They had learned not to take their good health for granted. One woman stated:

*“No one is guaranteed health, happiness, or peace of mind. We must learn to make the best of our situations whatever they may be. Just do the best that you can and things will turn out all right.”*

*Spirituality as a Recurrent Theme.* Spirituality was a recurrent theme. All of the women but one stated that they had become more spiritual after their cancer diagnoses. Spirituality for these women did not necessarily mean going to church more. In fact, many of them went less often during the active phases of their treatments. However, they cited praying more, alone, and with their children and spouses. They used meditation, read scripture regularly, and sought the help of pastors and their church families to alleviate emotional distress.

Data elicited from the participants described what it is like to live with breast cancer during the first year following diagnosis. Three overlapping phases of the experience were noted: a diagnostic phase, a treatment phase, and a post-treatment phase. A central concept emerged from each of the three periods: Impact, re-traumatization, and resolution/healing. All concepts led to the development of the central meaning statement expressed as an *experience that is a gradual, private, social, and spiritual process in which initial trauma takes place, re-traumatization occurs, and all efforts are directed at resolution/healing.*

## Discussion

The essence of the experience of living with breast cancer during the first year following diagnosis is that the experience is one of physical and emotional trauma related to diagnosis, re-traumatization as survivors go through treatment, and concerted effort towards resolution/healing. In general the findings were consistent with those reported from other research approaches to the problem. Similar to the findings of Vickberg et al.,<sup>44</sup> participants in all phases of the experience manifested intrusive thinking, and women with more intrusive thoughts reported more psychological distress than women with fewer intrusive thoughts. The use of the phenomenological approach affirmed the benefits of the mediating factors of emotionally expressive coping, effective support systems, spirituality, and the ability to make informed decisions identified by other authors.<sup>45-47</sup>

<sup>44</sup>Vickberg, 2000

<sup>45</sup>Bolger, 1997

<sup>46</sup>Gall, 2000

<sup>47</sup>Stanton, 2000

The phenomenological approach clearly demonstrated the dynamic nature of the experience of living with cancer and the error of assuming that women pass through linear, mutually exclusive stages as they live with cancer. Anxiety and fears, without regard for severity of disease, occurred and recurred

throughout the identified phases, indicating that health professionals, family, and friends should anticipate cyclic emotions and concerns from the patient.

A somewhat surprising finding was that for two of the participants, concern about body image was the deciding factor in choice of treatment. While altered body image has been recognized as a major fear or sequel to treatment,<sup>48</sup> the availability of lumpectomies rather than mastectomies and the advances in restorative surgery might possibly have been expected to reduce the proportion of women with this concern as a deciding factor for type of treatment.

<sup>48</sup>Carver, C.S., Pozo-Kaderman, C., Price, A.A., Noriega, V. Harris, S.D., Derhagopian, R.P., Robinson, D.S. & Moffat, F.L. (1998). Concern about aspects of body image and adjustment to early stage breast cancer. *Psychosomatic Medicine*, 60(2), 168-174.

The findings support the conclusions that a diagnosis of breast cancer is one that is psychologically, as well as physically, traumatic; that the treatment process, as well as the notion of living with a fatal diagnosis, results in suffering and re-traumatization; and that life with breast cancer in the year after diagnosis is characterized by both identifiable phases and “recycling” of fears and concerns. However, most women are resourceful and resilient, calling on innovative resources to minimize impact and augment resolution/healing. The central meaning statement captures the essence of the

women's experience during the first year after diagnosis with breast cancer.

Theoretical study findings have practice implications for the language used by health professionals and designers of health messages. In well-intended efforts to allay anxiety, some physicians were overly positive about the chances of a lump or suspicious mammogram proving to be benign, i.e., "at your age, this doesn't happen." To avoid undue distress if the lesion is cancerous, care providers may be advised to avoid impressions of certainty and to use more probabilistic language. Similarly, some women derived false comfort from health information, which emphasized the importance of a family history of breast cancer as a risk factor. While this is certainly essential information, the statement that breast cancer can occur in the absence of family history should also appear to reduce chances of giving women a false sense of security.

Implications for future research include the development of interventions for preventing or alleviating anxiety, intrusive thinking, and bouts with depression. Additional research is needed into the numbers of individuals who refuse treatment and their reasons for doing so. Longitudinal research is indicated to see how

these women are doing, emotionally as well as physically, in the years to come and after the support of the health care team is withdrawn. This study was limited by the relatively high socioeconomic status, and young age of participants. Further research should address the experiences of older women, women of color, those of low socioeconomic status, and those from rural areas.

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