

## ONLINE EXCLUSIVE

# Resolution of Spiritual Disequilibrium by Women Newly Diagnosed With Breast Cancer

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**Purpose/Objectives:** To describe the experience of restoring and maintaining spiritual equilibrium over a 14-month period by women newly diagnosed with breast cancer.

**Research Approach:** Qualitative approach, longitudinal design.

**Setting:** Urban breast cancer resource center.

**Participants:** 10 women initially one to five months from diagnosis, 5 of whom attended an eight-week self-transcendence theory-based breast cancer support group.

**Methodologic Approach:** Audiotaped interviews conducted within five months of diagnosis, two to three months later, and one year after that. Narratives were analyzed using Colaizzi's phenomenologic approach.

**Main Research Variables:** Spiritual disequilibrium resolution, breast cancer, self-transcendence.

**Findings:** Spiritual disequilibrium characteristics, as described in several studies of women with breast cancer, were fear of dying and a sense of aloneness in a struggle to maintain self-identity. Disequilibrium triggered all participants to reach outwardly for information and support from other people and faith resources and to reach inwardly to examine life values. Shortly after diagnosis, and continuing throughout the study period, most participants also reached outwardly to support others and conduct breast cancer advocacy work.

**Conclusion:** Resolving spiritual disequilibrium for women with newly diagnosed breast cancer means restoring a sense of connection to self, others, and/or a higher power. Self-transcendence views and behaviors evolving over time help women to restore their sense of connectedness, maintain hope for a future, and find renewed purpose and meaning.

**Interpretation:** An initial breast cancer diagnosis may be associated with spiritual disequilibrium that can be as problematic as the physical effects of cancer and cancer treatment. Women restore equilibrium through resolving their sense of disconnectedness and regaining a positive self-identity.

Shock and disbelief, fear, uncertainty, a sense of intense aloneness and isolation, and loss of control reflect a spiritual disequilibrium that occurs because cancer disrupts people's lives at least temporarily and perhaps permanently (Coward, 1997). Nurses observe differences in the manner that people resolve the spiritual impact of cancer on their lives. Knowledge of how some people restore spiritual equilibrium may help oncology nurses to assist people who are having trouble getting their lives back on track after cancer. This study explored the experience of resolving spiritual disequilibrium, defined as an uncomfortable sense of disconnection from self, others, and, sometimes, a higher power,

### Key Points . . .

- ▶ Initial breast cancer diagnosis and treatment are adverse events that may influence a woman's spiritual equilibrium negatively.
- ▶ The effort that some women must make to resolve spiritual disequilibrium is increased by adversities other than breast cancer.
- ▶ Women maintain and restore spiritual equilibrium by reaching outward to obtain and give support and by looking inward to examine current self-identity and life priorities.
- ▶ Sharing the experience with other women with breast cancer and breast cancer advocacy can be important ways for women to deal with breast cancer.

within the context of breast cancer diagnosis and treatment in a subset of 10 women participating in a larger study.

### Literature Review

Kemp (2001) suggested that people who are diagnosed with a life-threatening illness, such as cancer, suffer an increased sense of meaninglessness and hopelessness that can be relieved by an increase in sense of relatedness, forgiveness, or acceptance. Frankl (1963, 1969) proposed that people faced with adversity have an inherent capacity to relate to things outside of themselves and, through reaching out, they find renewed purpose and meaning in their lives. He labeled this capacity self-transcendence. Reed's (1989, 1991, 1996) conceptualization of self-transcendence, compatible with that of Frankl, involves expanding personal boundaries beyond the immediate or constricted view of self and the world as well as extending oneself beyond personal concerns and taking on broader life perspectives and purpose. The conceptual framework guiding this

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study was that the development over time of self-transcendence views and behaviors may describe how women with newly diagnosed breast cancer resolve the negative impact of cancer on their spiritual equilibrium.

Four qualitative studies with women several years after breast cancer diagnosis reported that women experienced spiritual disequilibrium before finding increased meaning or transformation within the context of cancer. Nelson (1996) studied nine women (aged 38–69) two to six years after diagnosis and treatment. Spiritual disequilibrium was manifested by hopelessness and depression, grief over real and imaginary losses, and fear of recurrence and early death. Women's struggle to find meaning was not relieved by the passage of time but was helped by relationship support and redefining what was most valued in their lives. Pelusi (1997), in her study of eight women (aged 34–70) 2–15 years post-therapy, also described an uncertain future and many losses as antecedents to a survivorship process that included helping others, locating resources for self, and increasing interest in maintaining health. Utley (1999) interviewed eight women (aged 65–77) 5.5–29 years postdiagnosis. Initially, the women experienced shock because they did not feel sick. In these women's past experiences, cancer meant suffering and death; therefore, they anticipated the same for themselves. However, their survival encouraged them to reach out to do more for themselves and others and to attach positive meaning to the event. Taylor's (2000) 24 study participants (aged 39–70, 2–27 months after initial diagnosis or recurrence) described the following characteristics of spiritual disequilibrium: a deepening sense of vulnerability, viewing death as an approaching threat, a disrupted life, and a negative impact on their families. Activities such as religious services and support groups, as well as reading, deep introspection, and respecting the healing action of time, assisted women during a process of finding positive meaning from their experience.

In a phenomenologic study of self-transcendence in five women with advanced breast cancer two to seven years post-diagnosis, participants recalled loss of self-confidence, depression, and fear of dying during the period of initial diagnosis (Coward, 1990). Women described the great effort required to reach inwardly or outwardly in the several ways that resulted in increased appreciation of their environment, ability to accept help from and give help to others, and ability to accept their situation. They also found new purposes to pursue when they no longer could participate in activities that previously helped to make their lives meaningful.

In summary, several studies have identified characteristics of spiritual disequilibrium in women with breast cancer and have described how women found hope and positive meaning in their cancer experience. All studies were one-time interviews, sometimes conducted years after initial diagnosis. Little is known about the actual experience over time of resolving spiritual disequilibrium that results from initial diagnosis and treatment of breast cancer. Additionally, little is known about how participation in support groups that promote self-transcendence views and behaviors may help to resolve spiritual disequilibrium. Several experimental studies have documented the beneficial impact of support group participation on the spiritual health of people with cancer (Cunningham & Edmonds, 1996; Hawks, Hull, Thalman, & Richins, 1995). The current study's primary investigator's clinical experience and pre-experimental research (Coward, 1998) indicated that group mutual support

helped to alleviate the negative impact of cancer on spiritual equilibrium. Therefore, the purposes of this study were to

- Explore, during a one-year period in women newly diagnosed with breast cancer, the experience of spiritual disequilibrium resolution.
- Compare that experience among women who did and did not participate in an eight-week closed support group based on self-transcendence theory.

## Methods

A longitudinal design and phenomenologic approach were used with a subset of women from a quasi-experimental pilot study. The larger sample study (Coward, 2003) examined patterns of effectiveness of participation in a theory-based breast cancer support group on self-transcendence views and behaviors and well-being. As women were recruited into the quantitative study ( $N = 41$ ), they were asked to consider discussing their experience with the researcher. The first five women enrolled into each of the intervention and comparison groups who agreed ( $n = 10$ ) contributed narrative data at the same time they completed the study questionnaire. Data were collected at three time points: when each woman entered the study (time [T] 1), after the eight-session support group (two to three months after baseline data collection for comparison group women) (T2), and one year after T2 (T3).

Institutional review board approval was obtained before the study began. Potential participants were referred by survivor volunteers at a breast cancer resource center and by nurses in local oncology settings.

## Procedures

Consent was obtained from participants prior to data collection. Most of the 30 narratives (three from each participant) were audiotaped by the primary investigator during half- to one-hour interviews in participants' homes. (Three participants chose to write about their experiences for one or more of their interviews.) At T1, women responded to the question, "Within the context of having breast cancer, what is difficult for you and what helps you feel better? Please describe your thoughts and feelings as completely as you can." Women responded to the same question at T2 and T3 but described cancer-related experiences since the date of the most recent previous interview.

## Analysis

Audiotapes and participant-written narratives were transcribed verbatim, edited, and printed for analysis. Data were analyzed separately for each time point. The analysis process was guided by the steps of phenomenologic analysis (Colaizzi, 1978).

1. Each narrative was read several times.
2. Statements related to spiritual disequilibrium and resolution were highlighted.
3. Meanings were formulated from the highlighted statements. For example, the following sentences from a subject's narrative were abstracted into a more general meaning.

[The evening I heard my diagnosis] I immediately went to a friend's house for the night. The next night I started feeling very anxious and I called a friend in California. And she stayed with me [on the telephone] for a couple of hours. The next day, she sent me a huge bouquet of

flowers. I'm a single woman living alone, and being alone has been a problem for me, so I felt her presence in the room when I got the bouquet. I needed to feel the presence of someone.

The meaning was that her normal pattern of feeling alone was intensified by hearing her cancer diagnosis; immediately reaching out to friends generated comfort.

4. The study coinvestigator read the narratives several times, reviewed the other investigator's choices of significant statements and meanings, clarified some of them, and pointed out additional interpretations of the data.
5. The meanings were organized, with a doctoral student's assistance, into theme clusters that captured the essence of participants' experiences at each time point.
6. The theme clusters were used to develop a detailed description of the longitudinal experience of spiritual disequilibrium resolution.
7. The description was integrated into a statement of the fundamental structure of the phenomenon.
8. To enhance the credibility of the analysis, the fundamental structure statement was reviewed by six study participants who agreed that it did describe their experience. Feedback was not obtained from four participants (one had died, one moved and left no forwarding address, and two did not respond to phone messages).

## Study Findings

The 10 participants ranged in age from 40–71 years ( $\bar{X} = 54.5$ ). All participants initially were one to five months beyond diagnosis of stage I or II breast cancer. Table 1, which presents participant characteristics by study group, reveals the similarities in demographic and disease characteristics. Table 2 presents participant pseudonyms and contextual data.

**Table 1. Participant Characteristics**

Characteristic	Support Group (n = 5)	Comparison Group (n = 5)
<b>Age (years)</b>	Range = 40–64 $\bar{X} = 49.8$	Range = 51–71 $\bar{X} = 59$
<b>Education (years)</b>	Range = 16–22 $\bar{X} = 18$	Range = 10–22 $\bar{X} = 17$
<b>Time since diagnosis (months)</b>	Range = 1–5 $\bar{X} = 2.8$	Range = 1–4 $\bar{X} = 2.1$
Characteristic	n	n
<b>Race or ethnicity</b>		
Caucasian	4	4
Asian American	1	–
African American	–	1
<b>Relationship status</b>		
Married	3	3
Single	2	2
<b>Breast cancer treatment<sup>a</sup></b>		
Mastectomy	4	4
Lumpectomy	1	1
Radiation	1	3
Chemotherapy	4	2

N = 10

<sup>a</sup> Participants could have undergone more than one type of cancer treatment.

**Table 2. Individual Study Participants**

Participant Pseudonym	Age (Years)	Time Since Diagnosis <sup>a</sup> (Months)	Occupation and Recent Personal History
Donna	40	1.5	Oncology nurse; recent arrival in state with husband and young child
Susan	47	3.0	Academic administrator; recently moved to area with husband and teenage daughter
Ciele	49	1.0	Homemaker and freelance writer; lives with husband and college-age daughter
Carole	49	3.5	Academic; Asian American, lives alone, only child away at college
Irene	51	3.5	Medical technologist in an oncology practice; lives with husband and teenage son
Chris	53	1.0	Homemaker; African American, lives alone, four grown children in area
Virginia	56	2.0	Homemaker; lives with husband whom she recently learned is unfaithful, newly married son and daughter-in-law in area
Karen	64	5.0	Artist; lives with unmarried adult son, husband and two grandchildren died in auto accident two years ago
Ellen	64	1.0	Nurse educator; lives alone, recently placed her elderly mother in a nursing home
Lois	71	3.0	Business trainer and consultant; lives with husband, estranged from only child

<sup>a</sup> Time since diagnosis was measured at time 1.

## Study Themes

Study findings are presented in increasing order of abstraction from theme clusters at each data collection time point (see Figure 1) to a detailed description of spiritual disequilibrium resolution to the statement of the fundamental structure of the phenomenon. Examples from individual participant experience clarify each theme within a cluster. Findings are not presented by study group because few differences existed in experiences of women regardless of whether they participated in the intervention.

**At the time of diagnosis:** Formulated meanings from the T1 significant statements were organized into themes representing participants' experience 1–5 months postdiagnosis ( $\bar{X} = 2.5$  months). Participants described shock, fear of dying, a sense of aloneness that compelled them to reach out for information and support, and a desire to help others or feel needed by others to maintain their sense of self-identity. Carole expressed shock and then panic so severe that she could not hear anything else her surgeon said. Her thoughts at that moment were similar to those of other participants, "How am I gonna die? And how long am I gonna live? . . . Breast cancer, in a way, defined what I'm going to have to deal with the rest of my life."

Although women expressed aloneness or isolation related to their disease, many also reported preexisting sources of existential aloneness (see Table 2). Carole felt isolated from her own body. But she also added, "Actually, it's not just breast cancer that I have. Breast cancer hits you around the age of 50 and it's about the time your children move away and it's about the time your body starts changing and it's sort of a transition period."

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### Time of Diagnosis

- Shock and fear of dying
- Sense of aloneness
- Trying to maintain self-identity
- Compelled to reach out for information and support
- Desiring to help others or feel needed by others

### Four to Seven Months Postdiagnosis

- Feeling more like their former selves
- Importance of supportive relationships
- Changes in insight facilitated behavioral changes.
- Fears about recurrence

### 14–18 Months Postdiagnosis

- Finding ways to prevent recurrence
  - Defining a new normal self
  - Change in priorities and relationships
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## Figure 1. Theme Clusters

Reaching out for support and information helped women to relieve panic and aloneness. Carole, comforted by reaching out to friends, also re-engaged in her passion for ballroom dancing. She explained, “I knew if I could keep myself happy and cheerful, I could get through it.” Virginia, believing that information would help to relieve her fear, immediately called a breast cancer survivor friend who sent her that same day to the breast cancer resource center. “I went down there with my head hanging low, but I left with it up high and not feeling so bad and alone. Knowing that both those ladies [survivor volunteers] had gone through cancer and they were both, you know, very healthy.” Susan reached out to current and former church communities and was surprised by people from her new church who “reached out in love in a way that was totally unexpected. And my previous church reached out as if we had never left.” Lois contacted her estranged adult son to ask his church to include her in prayer sessions. Chris and Ciele appealed directly to their faiths. Chris said, “I was upset, but I didn’t claim it. I put it into God’s hands.” Ciele said, “I really gave it all over to God: ‘I don’t know what to do, but I trust that you will help me figure it out.’ It was at that point I found the energy [to research treatment options].”

Participants also extended themselves to help others. Karen first said how much she appreciated gifts of food from friends after her husband and grandchildren died and after her bilateral mastectomy. She then remarked, “Interestingly, I have a friend who had a breast removed; she just went home yesterday, and my first thought was, ‘I can do something for her.’” Irene reached out to make friends with two women with breast cancer (one was Chris) at her oncology treatment center. “We basically formed our own support group of three.” Lois was angry with God at first because he let breast cancer happen to her. “Then I got scared that I better not be so arrogant, and I bargained with him, ‘If you’ll just take me off the hook, I will tell no less than one million women about getting themselves to the doctor in time.’” Lois began her witnessing at a Mother’s Day service at her son’s church. She talked not only about God reminding her to schedule her mammogram and her subsequent successful surgery, but also about how her family was reunited after eight years of estrangement. Chris was sure that something was wrong with her breast, but it was a year before she was diagnosed. Throughout her interview, she told the researcher to tell others to be persistent and obtain second opinions if necessary. Chris also believed that her faith

and positive attitude got her through surgery. She, like Lois, wanted to tell others: “I hope I can benefit something out of it by talking to others how I went through it. Because it wasn’t only the doctor that was there [during her surgery]. It was God that was there.”

Helping others and feeling needed helped women to maintain their self-identity and distracted them from feelings of aloneness. Lois derived self-worth from witnessing and continuing to teach management skills. When Carole was not interacting with her students or other faculty, she felt isolated and more frustrated with physical limitations resulting from reconstructive surgery. Donna revealed, “My six-year-old has continued to be himself, but that is supporting. His demands and needs for attention keep me fixed in reality and sane.”

In summary, fear of dying, other cancer unknowns, and a sense of aloneness compelled study participants to call upon friends, family, faith resources, and their own inner resources for information and support and to maintain their own sense of self-worth. Even at this early stage in their cancer journey, some participants found positive support and meaning through their contacts with other women with breast cancer.

**Themes four to seven months postdiagnosis:** By the time of the second interview ( $\bar{X} = 5.2$  months since diagnosis), although women felt less frightened and more like their former selves, they continued to express the importance of supportive relationships. Some self-change was noted, and fears about recurrence were expressed. Carole felt better because her physical condition had improved. Lois wrote that her physical recovery was almost complete but added that she vividly remembered the shock of her diagnosis. Donna maintained her self-identity with help from her young son. She said, “My six-year-old’s demands help me still feel like a mom.”

For several women, returning to normal was associated with career self-identity. Carole was “excited about getting back to teaching and research and to a more structured life.” Karen, referring to a recent intensive workshop for artists that she attended in Seattle, WA, stated, “It was very satisfying to know I haven’t lost it; my creativity and the ability to produce under stress is still there.” Donna, who was not working during her treatment, was pleased that her support group helped her “still have a chance to be a little bit of a nurse.” She also viewed her online cancer support group as an opportunity to answer questions for others. Irene’s own chemotherapy experience helped her and her coworkers to better understand why they should “get lab results out quickly and to make sure they are accurate.” Lois described her business as her “best healing process.” Ellen experienced a threat to her identity when a perhaps well-meaning administrator pulled her out of her usual clinical assignment even though her physician had cleared her to work. She wrote, “[This was] a devastating message of ‘professional nonworth’ that I have not been able to overcome.”

Supportive relationships with other women with breast cancer were of prime importance. Susan, Donna, Carole, Ciele, and Karen experienced the theory-based intervention support group. (Intervention session activities are detailed in Coward, 2003.) Susan was surprised at how much care she developed for her support group members. Donna, as did Susan, found that her group made her “feel like I am not the only one having some of the feelings that I’ve had.” Carole, Ciele, and Karen derived benefit by comparing themselves favorably to

other members: Carole and Ciele because they did not need chemotherapy, and Karen because she was not burdened by working and caring for young children while receiving chemotherapy.

With the exception of Ellen, women from the comparison group who did not receive the study intervention also described valued relationships that they developed with other women with breast cancer. Irene formed a close friendship with one woman in her “support group of three.”

I went to radiation first, and she had chemo first. I answer her questions about radiation. And she understands where I'm coming from. We talked about the loneliness and what you actually face and that no matter who you discuss it with, they don't understand it unless they've done it themselves.

For Chris, Irene and the other woman were the “best things that could ever happen” to her, not just for sharing information but also for laughing together while comparing surgery scars, shopping for wigs and hats, and simply being positive.

Relationships with God, friends, family members, and even casual contacts were sources of support and opportunities to provide support. Chris' new “chemo” friends may have kept her “going and laughing and enjoying life,” but God was primary because he was there for her when others were not. Ciele's help came from her two breast cancer support groups, her family, and her struggling relationship with God. Her struggle was, “How do I live my life each day in the present moment with some sense of joy, and not just going and doing, and trust God enough to help me do that?” Virginia continued to be uplifted by her circle of friends who loved her. Although exhausted by chemotherapy, Virginia made the effort to be among friends because of the energy they gave her. She believed that her friends purposely “kept her in motion” so she would not be depressed. Karen talked about the renewed energy she received from visiting old friends in Seattle. Donna spoke of a somewhat unusual source of support. “When you go to the grocery store and someone says, ‘have a nice day,’ you know you usually just blow it off. Well, I take that now. I say, ‘thank you,’ and I take it because I need it.”

Several women reported changes in values that facilitated behavioral changes. Carole recognized that she needed a companion and had started to date a man she met at dance class. Although it was important to Donna to “still feel needed,” she was beginning to understand and accept the need of others to help her. The insight of Irene and her coworkers about the importance of laboratory results led to more careful blood laboratory assessments. Ciele described being more assertive in pursuing treatment options, looking for ways to be healthy, and setting priorities for her use of time.

Now that most women were finishing treatment successfully, they gave voice to fears about recurrence. Carole's oncologist did not believe that her “good natured” tumor required tamoxifen treatment, but she began taking it because she wanted to do everything possible to prevent a recurrence. Lois, Ciele, Karen, and Chris described usually feeling safe, but each experienced nagging fear. As Lois wrote, “Once cancer strikes, the body is vulnerable to a repeat occurrence. I find myself in a state of fear one moment then reassurance the next.”

In summary, by the time most women completed breast cancer treatment, although they had experienced return to their physical, emotional, and career-identified selves prior to

diagnosis, they also reported changes in views and behaviors indicative of expansion of self-concept boundaries. Ongoing relationships with their faith communities and God, family, friends, and other women with breast cancer provided opportunities to receive and give support. Concern about cancer recurrence kept women from feeling safe.

**Themes 14–18 months postdiagnosis:** By the time of the third interview ( $\bar{X}$  = 16.5 months since diagnosis), women were finding ways to prevent recurrence, identifying themselves differently from their previously normal selves, and changing priorities and relationships as a result of having breast cancer. Although their experience was, in some ways, similar to what they described four to seven months after their diagnosis, women now were more sure of themselves and their places in their world.

Although they described feeling anxious around the time of their first anniversary follow-up, women felt safer from recurrence the further they were from time of diagnosis. All described steps that they were taking to lessen their chances of recurrence. Lois depended on her pact with God to keep her healthy. Chris maintained a positive attitude and kept active to prevent a recurrence but said that her faith would help her to accept an eventual recurrence. Everyone, except Irene and Ellen, reported setting goals for themselves to stay mentally positive and physically active. Virginia, Susan, and Ciele felt threatened when friends had recurrences. However, Virginia noted that two of her church friends with recurrences were models for being “strong and still encouraging the rest of us.”

Women self-identified differently than they did at the earlier interviews. For some women, their new normal was associated with new behaviors. Carole, who earlier described herself as a “loner,” now had a live-in companion. Carole's insight into her own needs helped her to better state her feelings within that relationship. Ciele, now more accepting of her own and others' faults, said, “If it's not life threatening, how important is it really?” She also conserved her energy so that she could act out her new priorities. Ellen expressed pleasure and renewed sense of self-worth because both her surgeon and a coworker disclosed that she had been a model to others for how to handle cancer treatment. Irene described driving alone on a long trip to her home state of Tennessee as an emotional high that left her believing again that she had a future. She wrote, “I don't know what that future is, or how it will be altered, but I think I can accept any compromises that will be required.” Irene had not mentioned her faith in previous interviews, but she may have rediscovered it. She wrote that her return to Tennessee made her realize why the Smoky Mountains were so important to her. She quoted Psalm 121, “I lift my eyes to the hills. From whence does my help come? My help comes from the Lord.”

### Detailed Description of Spiritual Disequilibrium Resolution

Characteristics of spiritual disequilibrium related to diagnosis of breast cancer were similar for all 10 women. Fears of dying and aloneness associated with having a life-threatening condition threatened the maintenance of their self-identity as healthy and productive women. Most participants revealed additional concurrent sources of spiritual disequilibrium.

Attempts to resolve spiritual disequilibrium began early in the diagnostic and treatment period. All but two participants

reached out immediately to other people and/or God for support or information to relieve their sense of fear and aloneness. Each woman described the comfort and sense of connection she received after reaching out. One participant, choosing to not immediately worry friends or family, found that her surgeon's "sincere, respectful, and caring concern" gave her "the courage to face the situation with a positive attitude."

Most women, early in their diagnosis and treatment course, found that helping others helped to maintain their own self-identity. Continuing to honor work or childcare commitments also preserved a sense of normalcy and served as a means to redirect self-worry. Helping other women with breast cancer directly, or advocating in general for screening and better diagnosis, helped to create meaning. For some women, discovery of meaning happened after treatment. One woman found meaning and restoration of self-worth more than a year later when learning that she was an inspiration to her surgeon and coworkers.

Connections with God and others continued to be supportive and provided opportunity to give support throughout the study time period. Five participants' ongoing relationships with God or their church communities helped them to overcome fear and aloneness. All but one participant formed helpful relationships with other women with breast cancer. Such relationships provided opportunities to share experiences and problem solve with others who were empathetic and knowledgeable. The one participant, although she did not describe connections with other women with breast cancer during the study, later joined a breast cancer support group in which she remains active.

Preserving or returning to normalcy was associated with increased understanding that normal was not the same as before their cancer diagnosis. Women regained their self-identity as physically and mentally healthy people with work, family, and social roles to fulfill. But, as one woman described, her physical body was different and her life values had changed from a focus on her career to a commitment to spend more time on herself and with her family.

Reaching outwardly and inwardly led to changes in priorities and relationships with God and others. During the course of the study, women became more aware of personal needs and were more assertive on their own behalf and for others. Although women were less fearful of cancer after completing treatment, most expressed concerns about recurrence. Meeting other women with recurrent cancer and the approach of their own cancer anniversary were occasions for worry. Reliance on faith in God and in their own behavior increased their hope for survival. Maintaining their faith and doing good works increased women's confidence in their ability to stave off recurrence, as did making lifestyle changes related to physical activity, nutrition, and stress reduction.

### **The Fundamental Structure of Spiritual Disequilibrium Resolution**

Spiritual disequilibrium in women with breast cancer is characterized by fear of dying and of other unknowns associated with cancer and a sense of aloneness in a struggle to maintain current self-identity. Spiritual disequilibrium compels women to reach outwardly toward their faith and other people for support and information to decrease their fear and aloneness and to reach inwardly for strength and to examine previous life values.

Treatment effects, as well as disruption of support resources for reasons unrelated to cancer, increase the effort that some women must make to restore confidence in their bodies and in their sense of future. More than a year after diagnosis, women continued to contemplate their own vulnerability. Restoring self-identity and confidence in their ability to live meaningfully involves faith in God, learning from others' experiences, finding an individual recipe for staying healthy, and using personal experiences to help others detect and survive breast cancer.

### **Discussion and Interpretation**

This study explored the experience of spiritual disequilibrium and resolution over time and within the context of the potentially life-threatening event of cancer. Participants described their positive and negative experiences with breast cancer diagnosis and treatment. Although women were not asked directly about spiritual matters, their responses indicated that their diagnosis activated spiritual concerns such as fear of dying, sense of aloneness, and disrupted self-concept. Other negative life events interfered with some women's ability to regard their cancer diagnosis as a major threat to their spiritual equilibrium. However, all study participants experienced a sense of vulnerability and existential aloneness that was frightening to them. Most women reached out immediately after diagnosis for information and support that, when obtained from a variety of sources, helped them to normalize their experience and to feel better spiritually.

Data analysis and interpretation were complicated and time consuming because of the longitudinal nature of the data and the desire to observe similarities and differences among women who did and did not participate in the theory-based support group. Findings from this small group of women are not meant to be generalized but rather illuminate the lived experience of a complex phenomenon that evolves over time and may be common to other women who are diagnosed with breast cancer.

Few discernible differences existed among participants in the intervention and comparison groups in demographic and disease characteristics or in their experience of spiritual disequilibrium resolution. Participants in the support group intervention found that other group members were a powerful resource. Sharing experiences (and sometimes crying together) helped them to cut through what one called "the superficial stuff" to make connections that eased confusion and helped them feel not so alone. However, women in the comparison group made similar meaningful connections with other women with breast cancer. Some women from both groups drew on their faith for support and found comfort from God and fellow church members. Women in both study groups also found meaning in witnessing for improvement in detection and treatment of cancer and were successful in maintaining or regaining their self-identity. Women in both groups participated equally in church and social groups, including other cancer support groups.

Women's experiences in this longitudinal study were similar to those of women with breast cancer in other qualitative studies (Halstead & Hull, 2001; Nelson, 1996; Pelusi, 1997; Taylor, 2000; Utley, 1999). Findings from all studies indicate that a breast cancer diagnosis is accompanied by senses of fear, loss, and vulnerability and threatens women's self-confidence as healthy, social beings with identified purposes and

sources of meaning in their lives. Women, by reaching out to their God or church communities, families, and friends for support and information, maintained or regained spiritual equilibrium and found purpose and meaning from the experience. Similar resources for developing meaning were reported by people with cancer in O'Connor, Wicker, and Germino (1990). Relationships with other women with breast cancer were described as especially helpful in this and other studies (Cope, 1995; Pelusi). Altruism as a resource for creating meaning was described in terminal illness (Coward, 1990, 1994; Yalom, 1982) but not as occurring early in a disease process. In the first months of their cancer journey, women in this study shared experiences and problem solved with others, witnessed about how faith helped them to survive cancer treatment, and encouraged others to be assertive with healthcare providers. Such activities provided participants with a renewed sense of purpose and served as a means to create personal meaning that was spiritually healing.

Participants also engaged in introspection to clarify personal values related to work and social roles. Clarifying, and sometimes modifying, beliefs and behaviors relieved spiritual distress through restoring a sense of control, self-confidence, and hope for the future. New insights also facilitated communication within important relationships with God, family, and friends that helped participants to restore a sense of purpose and meaning in their lives. That an adverse life event can initiate a search for meaning was the focus of Frankl's (1963) work and cancer research by nurse researchers and social psychologists (Dow, Ferrell, Haberman, & Eaton, 1999; Lewis, 1989; O'Conner et al., 1990; Steeves & Kahn, 1987; Taylor, 1983, 1995, 2001; Thompson & Janigian, 1988; Thompson & Pitts, 1993).

Expanding self-conceptual boundaries through introspection and reaching out to accept and give support are characteristics of self-transcendence (Reed, 1996; Frankl, 1969). Erikson (1963) proposed that gradual evolutions of meaning develop over the life span toward a "generativity" stage exemplified by self-transcendence activities. However, the diagnosis of a potentially life-threatening condition may precipitate a reaching out and an evaluation of previous life goals and sources of meaning at any age (Thompson & Pitts, 1993). As such, a cancer diagnosis may be a pivotal life event in that decisions made in the context of diagnosis and treatment may have far-reaching consequences for healing (Coward, 1997; Coward & Reed, 1996; Taylor, 1995).

Women relied on their faith in God and on their own intuition to maintain good health and prevent recurrences. Such actions enhanced their sense of control and increased their hope in a healthy future. A recent review of recurrence and survival outcomes associated with health behavior and psychological interventions indicated that, although no survival benefits have been reported from the as-yet small database, several studies in women with breast cancer reported better functional status associated with positive diet and exercise behavior change (Andersen, 2002).

## Implications for Nurses

The study findings have several implications for oncology nurses. Women in this study were surprised and pleased when emotional or spiritual support came from unexpected sources

such as people they did not know well or did not know at all. Even a simple gesture, such as a smile from a nurse walking by the outpatient waiting room, can have unanticipated positive meaning to someone who is feeling lonely. When appropriate, starting a dialogue with a woman about fear and isolation related to cancer may help to normalize that woman's experience and help her to feel as though she is not alone.

Although nurses may discuss various spiritual concerns at the time of diagnosis, women go through the process of awareness and resolution of spiritual disequilibrium at their own pace. The nurse, at each point of contact, can encourage women to consider the significance of cancer in their lives and to suggest that other people find that this time is an opportunity to clarify what is most meaningful to them.

Although each woman's breast cancer experience is unique, other women do share similar concerns. Sharing experiences related to breast cancer not only helps women to normalize their experience but also provides them with opportunities to assist others to achieve better spiritual and physical outcomes. Nurses can maintain an "on-call" list of women who offer to support others with breast cancer. Another resource is a current list of cancer support groups that includes a group contact person. Women have differing needs for group support, and groups vary in purpose and encouragement of peer group interaction (Cunningham & Edmonds, 1996; Fobair, 1996). Helping women access information about group focus and leadership provides a model of supportive behavior on the part of the nurse and aids reluctant or overwhelmed women to more easily seek out further details.

Some women may be receptive to a group that combines art and peer support. A source of spiritual healing in two recent studies was the sharing of experience among women with breast cancer while expressing feelings about cancer in a piece of art (Heiney & Darr-Hope, 1999; Predeger, 1996). Findings from the current study and Swirsky (1996) also suggest that referring women to resources for breast cancer advocacy provides an environment for support and communication that is healing.

## Research Recommendations

Most of the women with breast cancer in this and the other studies were well-educated Caucasian Americans. The African American participant, at each data-collection time point, discussed the primary importance of her relationship with God. Lackey, Gates, and Brown (2001) also reported that prayer and reliance on God's healing power relieved African American women's fears about death from breast cancer. Is faith a primary resource for all African American women? How is spiritual disequilibrium experienced and resolved in women who are less educated or from other ethnic groups and in other countries? Some work has been done on finding meaning with women with breast cancer in Denmark (Jensen, Back-Petersson, & Segesten, 2000), England (Luker, Beaver, Leinster, & Owens, 1996), and Taiwan (Chiu, 2000), but more is needed.

Women's successful strategies for resolving spiritual disequilibrium will be used in future community support group intervention studies. However, relatively few people participate in such groups and those who do primarily are middle-class Caucasian women (Barg & Gullatte, 2001; Krizek, Roberts, Ragan, Ferrara, & Lord, 1999). Other group interventions

need to be studied, such as church-centered groups, single-culture groups (e.g., Sisters Network for African American women), and chemotherapy center groups organized around patient appointment times or social events.

Journalist Marc Barasch (1993) wrote that when he was diagnosed with cancer, his doctor said, "First take care of the physical problem and then you can go back to worrying about your inner life" (p. 16). Barasch argued for the exact opposite. In such moments of crisis, he believed that what is most needed is to fully experience what is happening and make it a part of a larger process of becoming. Oncology nurses can assist women diag-

nosed with breast cancer to resolve their sense of disconnectedness from themselves, others, and their faith. In so doing, nurses may have a positive impact on women's sense of hope for their future and in renewed purpose and meaning in their lives.

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## References

- Andersen, B. (2002). Biobehavioral outcomes following psychological interventions for cancer patients. *Journal of Consulting and Clinical Psychology, 70*, 590–610.
- Barasch, M. (1993). *The healing path*. New York: Penguin Group.
- Barg, F., & Gullatte, M. (2001). Cancer support groups: Meeting the needs of African American women with cancer. *Seminars in Oncology Nursing, 17*, 171–178.
- Chiu, L. (2000). Lived experience of spirituality in Taiwanese women with breast cancer. *Western Journal of Nursing Research, 22*, 26–53.
- Colaizzi, P. (1978). Psychological research as the psychologist views it. In R. Valle & M. King (Eds.), *Existential-phenomenological alternatives for psychology* (pp. 48–71). New York: Oxford University Press.
- Cope, D. (1995). Functions of a breast cancer support group as perceived by the participants: An ethnographic study. *Cancer Nursing, 18*, 472–478.
- Coward, D. (1990). The lived experience of self-transcendence in women with advanced breast cancer. *Nursing Science Quarterly, 3*, 162–169.
- Coward, D. (1994). Meaning and purpose in the lives of persons with AIDS. *Public Health Nursing, 11*, 331–336.
- Coward, D. (1997). Constructing meaning from the experience of cancer. *Seminars in Oncology Nursing, 13*, 248–251.
- Coward, D. (1998). Facilitation of self-transcendence in a breast cancer support group. *Oncology Nursing Forum, 25*, 75–84.
- Coward, D. (2003). Facilitation of self-transcendence in a breast cancer support group: II. *Oncology Nursing Forum, 30*, 291–300.
- Coward, D., & Reed, P. (1996). Self-transcendence: A resource for healing at the end of life. *Issues in Mental Health Nursing, 17*, 275–288.
- Cunningham, A., & Edmonds, C. (1996). Group psychological therapy for cancer patients: A point of view, and discussion of the hierarchy of options. *International Journal of Psychiatry in Medicine, 26*(1), 51–82.
- Dow, K., Ferrell, B., Haberman, M., & Eaton, L. (1999). The meaning of quality of life in cancer survivorship. *Oncology Nursing Forum, 26*, 519–528.
- Erikson, E. (1963). *Childhood and society*. New York: W.W. Norton.
- Fobair, P. (1996). Cancer support groups and group therapies: Part 1. Historical and theoretical background and research on effectiveness. *Journal of Psychosocial Oncology, 15*(1), 63–81.
- Frankl, V. (1963). *Man's search for meaning: An introduction to logotherapy*. New York: Pocket Books.
- Frankl, V. (1969). *The will to meaning*. New York: New American Library.
- Halstead, M., & Hull, M. (2001). Struggling with paradoxes: The process of spiritual development in women with cancer. *Oncology Nursing Forum, 28*, 1534–1544.
- Hawks, S., Hull, M., Thalman, R., & Richins, P. (1995). Review of spiritual health: Definition, role, and intervention strategies in health promotion. *American Journal of Health Promotion, 9*, 371–378.
- Heiney, S., & Darr-Hope, H. (1999). Healing icons: Art support program for patients with cancer. *Cancer Practice: A Multidisciplinary Journal of Cancer Care, 7*, 183–189.
- Jensen, K.P., Back-Pettersson, S., & Segesten, K. (2000). The meaning of "not giving in": Lived experiences among women with breast cancer. *Cancer Nursing, 23*, 6–11.
- Kemp, C. (2001). Spiritual care interventions. In B. Ferrell and N. Coyle (Eds.), *Textbook of palliative nursing* (pp. 407–414). New York: Oxford University Press.
- Krizek, C., Roberts, C., Ragan, R., Ferrara, J., & Lord, B. (1999). Gender and cancer support group participation. *Cancer Practice, 7*, 86–92.
- Lackey, N., Gates, M., & Brown, G. (2001). African American women's experiences with the initial discovery, diagnosis, and treatment of breast cancer. *Oncology Nursing Forum, 28*, 519–527.
- Lewis, F. (1989). Attributions of control, experienced meaning, and psychological well-being in patients with advanced cancer. *Journal of Psychological Oncology, 17*(1/2), 105–119.
- Luker, K., Beaver, K., Leinster, S., & Owens, R. (1996). Meaning of illness for women with breast cancer. *Journal of Advanced Nursing, 23*, 1194–1201.
- Nelson, J. (1996). Struggling to gain meaning: Living with the uncertainty of breast cancer. *Advances in Nursing Science, 18*(3), 59–76.
- O'Connor, A., Wicker, C., & Germino, B. (1990). Understanding the cancer patient's search for meaning. *Cancer Nursing, 13*, 167–175.
- Pelusi, J. (1997). The lived experience of breast cancer. *Oncology Nursing Forum, 24*, 1343–1353.
- Predeger, E. (1996). Womanspirit: A journey into healing through art in breast cancer. *Advances in Nursing Science, 18*, 48–58.
- Reed, P. (1989). Mental health of older adults. *Western Journal of Nursing Research, 11*, 143–163.
- Reed, P. (1991). Self-transcendence and mental health in oldest-old adults. *Nursing Research, 40*, 5–11.
- Reed, P. (1996). Transcendence: Formulating nursing perspectives. *Nursing Science Quarterly, 9*, 2–4.
- Steeves, R., & Kahn, D. (1987). Experiences of meaning in suffering. *Image, 19*, 114–116.
- Swirsky, J. (1996). Response to "social support and adjustment to breast cancer." *Scholarly Inquiry for Nursing Practice, 10*, 129–133.
- Taylor, E.J. (1995). Whys and wherefores: Adult patient perspectives of the meaning of cancer. *Seminars in Oncology Nursing, 11*, 32–40.
- Taylor, E.J. (2000). Transformation of tragedy among women surviving breast cancer. *Oncology Nursing Forum, 27*, 781–788.
- Taylor, E.J. (2001). Spirituality, culture and cancer care. *Seminars in Oncology Nursing, 17*, 197–205.
- Taylor, S. (1983). Adjustment to threatening events: A theory of cognitive adaptation. *American Psychologist, 38*, 1161–1173.
- Thompson, S., & Janigian, A. (1988). Life schemes: A framework for understanding the search for meaning. *Journal of Social and Clinical Psychology, 7*(2/3), 260–280.
- Thompson, S., & Pitts, J. (1993). Factors relating to a person's ability to find meaning after a diagnosis of cancer. *Journal of Psychosocial Oncology, 11*(3), 1–22.
- Uitley, R. (1999). The evolving meaning of cancer for long-term survivors of breast cancer. *Oncology Nursing Forum, 26*, 1519–1523.
- Yalom, I. (1982). The "terrestrial" meaning of life. *International Forum for Logotherapy, 5*(2), 92–102.