

Survivor Loneliness of Women Following Breast Cancer

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In the years beyond diagnosis and acute treatment, the physical, emotional, and social effects of breast cancer may create ongoing challenges and crises that trigger the acute experience of loneliness.

Women live with physical reminders (e.g., scars, sweats and hot flashes, fatigue, lymphedema, sexual difficulties), emotional sequelae (e.g., emotional upset and distress, alarm that any ache or pain signals recurrence, uncertainty about the future), and social challenges (e.g., pressure to get past the experience and “get back to normal,” the burden of sustaining a heroic survivor narrative) (Arman, Rehnsfeldt, Lindholm, Hamrin, & Eriksson, 2004; Ganz, 2005; Gill et al., 2004; Hoybye, Johansen, & Tjornhoj-Thomsen, 2005; Landmark, Strandmark, & Wahl, 2001; Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2005; Sinding & Gray, 2005). The sheer volume and interplay of those factors may create ongoing challenges and crises that cause the experience of loneliness.

After the acute phase of breast cancer treatment, researchers have found that women continue to experience high levels of emotional distress (Aranda et al., 2005; Carlsson, Arman, Backman, & Hamrin, 2005; Cartwright-Alcares, 2005; Knobf, 2007) as they seek a sense of personal meaning and growth from the experience (Hoybye et al., 2005; Landmark et al., 2001). Existential philosophy has characterized loneliness as emerging from the realization of one’s mortality and the meaning this gives life, including the idea that inner growth often is preceded by suffering (Heidegger, 1927/1962; Kierkegaard, 1843/1985; Moustakas, 1972, 1989; Sartre, 1957; Tillich, 1963). The struggle to find meaning in a personal crisis, such as breast cancer, has been proposed to heighten people’s consciousness of self, the world, and others and may be a precursor to loneliness (Mayers & Svarthberg, 2001; Portnoff, 1976). Loneliness may be among the psychosocial variables embedded in women’s experiences following breast cancer (Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002; Samarel, Tulman, & Fawcett, 2002). Despite the 2.4 million breast cancer survivors in the United States and millions more worldwide (American Cancer Society

Purpose/Objectives: To describe the experience of loneliness for women more than a year following breast cancer treatment.

Research Approach: Qualitative, phenomenologic.

Setting: Interviews conducted in women’s setting of choice (e.g., home, library).

Participants: Purposive sample of 13 women, 1–18 years following breast cancer treatment.

Methodologic Approach: Streubert’s descriptive phenomenologic method based on Husserl’s phenomenology.

Main Research Variables: Phenomenon of loneliness.

Findings: Women conveyed a unique description of loneliness that was termed *survivor loneliness*. They described how they felt alone in the awareness of mortality and were invalidated in the experience of ongoing symptom burden, a changed sense of identity and connection, and an altered threshold for distress that pervaded their long-term experiences. As they sought ways to lead more authentic lives, the women sometimes withheld truth or projected images they perceived as inauthentic, contributing to their loneliness. Paradoxically, as survivors perceived connections with others as more fragile, they also felt a strengthened vitality of connection, particularly with their children, and a deepened sense of empathy and connectedness to the suffering of others.

Conclusions: Findings shed light on the ongoing symptom experience of women and the isolation they experienced as they sought to work through an altered sense of self, connection, and identity as breast cancer survivors. Although survivor loneliness was experienced by all participants, findings suggest that some women may be more vulnerable to heightened psychological distress. Follow-up care should include giving recognition to survivors’ experiences and normalizing the situation to allow for survivors’ expressions of experience.

Interpretation: Through attentive and empathic assessment, clinicians need to be alert to the unmet needs of longer-term survivors, including the experience of survivor loneliness and the importance of identifying and assisting survivors who describe heightened distress. Prospective studies are needed to examine survivor loneliness and the factors that make some women more vulnerable to psychological distress. Grounded theory studies are needed to delineate the phases and challenges of breast cancer survivorship, including survivor loneliness.

[ACS], 2008a), no studies have explicitly investigated the phenomenon of loneliness for women more than one year following breast cancer treatment.

The current phenomenologic study arose from the author's clinical practice as a psychiatric nurse practitioner. In that clinical setting, several breast cancer survivors conveyed high levels of emotional distress as they sought to find a sense of personal meaning and growth from the cancer experience. Women frequently used the word *lonely* to describe how they felt when others failed to understand their ongoing symptom burden, fears of recurrence, and heightened need to find meaning in their lives. A review of the conceptual nursing literature showed that the concept of loneliness primarily has been viewed as a social deficit or pathologic phenomenon; however, the belief does not capture the depth or multifaceted ways breast cancer survivors described their experience (Rosedale, 2007). A review of the research literature concerning loneliness and breast cancer revealed a paucity of findings. A qualitative study of Internet breast cancer support group participants identified the word *lonely* in 100% of the narratives (Hoybye et al., 2005). Two quantitative studies reported the incidence of loneliness as measured by the revised University of California Los Angeles (UCLA) Loneliness Scale (Fogel et al., 2002; Samarel et al., 2002). No studies examined the loneliness experience from the perspective of survivors. To address the gap in the literature, the current phenomenologic study describes the experience of loneliness for women more than a year following breast cancer treatment.

Methods

A descriptive, phenomenologic study based on Husserl's (1913/1962) phenomenology and Streubert's (1991) nurse-developed methodology was used to study the phenomenon of loneliness for breast cancer survivors. In addition, Streubert was the consulting methodologist throughout the study. Nursing's social policy statement (American Nurses Association, 2003) indicated that nursing practice is characterized by attention to the full range of human experience and the integration of knowledge gained from understanding of patients' subjective experiences. The ideas underpin Streubert's descriptive method.

Sample

Participants were recruited from a volunteer list at Reach to Recovery, a cancer survivors' network sponsored by ACS. According to ACS (2008b), "Reach to Recovery works through carefully selected and trained volunteers who have fully adjusted to their breast cancer treatment. All volunteers complete an initial training and participate in ongoing continuing

education sessions." Women participating in the study were aged 18 years or older, completed active treatment for breast cancer a year or more prior to study, and spoke and understood English. Exclusion criteria included women who experienced cancer recurrence during the course of the study or who experienced other major unstable, systemic diseases (e.g., unstable hypertension). Protection of human subjects was assured and approved by an institutional review board. Participants signed consent forms and confidentiality was protected.

Data Collection

Interviews: The researcher conducted initial open-ended interviews that lasted approximately 90 minutes at sites selected by the participants. Participants completed a demographic and treatment questionnaire and were asked to describe their experience of loneliness. They also were encouraged to share written and artistic expressions that shed light on their experience. Women brought journal entries, photographs, poetry, and stories they had written. The personal expressions were used to prompt informants about their experience and revealed various dimensions of the phenomenon for a more holistic and exhaustive description. The participants' explication of the written words and artwork were further used for depth of description (e.g., "It says here in your journal that you felt lonely, please describe that experience.")

The interviews were audiotaped and the data were transcribed verbatim by a transcriptionist. In addition, the researcher replayed audiotapes and reviewed each transcription personally, making changes and clarifications if necessary. Audiotaping assisted the researcher in recreating the interview and facilitated immersion in the data and data analysis.

Field notes: During and immediately following interviews, the researcher recorded field notes. The notes included the researcher's impression of the interview, nonverbal behaviors, and emotional responses (tone of voice and affective changes observed during the interview). Furthermore, the notes included the researcher's initial thoughts about women's creative works, such as metaphors used.

Reflexive journal: The researcher maintained a reflexive journal about thoughts, feelings, and associations during the interviews, transcriptions, analysis, and synthesis of the data. Preliminary codes, emerging themes, and developing theoretical assumptions were recorded as they occurred.

Data Analysis

The researcher carefully read the interview transcripts to obtain a general sense of the experience, reviewed the transcripts to uncover essences, apprehended essential relationships, and developed a

formalized description of the phenomenon. Consistent with Streubert Speziale and Carpenter (2003), analysis occurred throughout data gathering. The researcher's reflexive journal also facilitated phenomenologic reduction. The researcher became immersed in the data, reading and rereading transcriptions, field notes, and journal entries. Atlas.ti 5.0 was used to assist analysis. In this process, significant statements were identified. Examples of how the essences link to words of the participants and their creative works constitute the audit trail. A portion of the audit trail for data analysis can be found in Table 1.

Study Rigor

The researcher tested for trustworthiness, fittingness, and auditability using prolonged engagement with the subject matter and member checking (conducting additional meetings, phone calls, and electronic mail

exchanges to validate themes, incorporate content, and ensure that the formalized description was "true" to participants' experiences). Trustworthiness of the data was established when all the participants confirmed that the formalized description accurately captured their experience of loneliness (Streubert Speziale & Carpenter, 2003). Fittingness was accomplished when participants confirmed that the formalized description represented their experience as a whole (Streubert Speziale & Carpenter). Validation of the researcher was accomplished by having a group of qualitative researchers work with the researcher throughout the study to examine the data, compare codes, challenge interpretations, and expose and question bias. In addition to the methodologist, two qualitative nurse researchers consulted with the group. Auditability was achieved by using a tape recorder to record the interviews, transcribing the interviews verbatim, checking

Table 1. Selected Examples of Essences Illustrating Participant Statements and Supporting Creative Expression

Essence	Illustrating Participant Statement	Supporting Creative Expression
Emerging consciousness	I think that loneliness, when you go through something and realize, "Oh, we're not immortal," I think that heightens your awareness and you have to own your loneliness.	The woman wrote a poem called "Feeling Lonely" in her journal. She wrote, "It arises unexpectedly and then I am aware of feeling lonely."
Transcending time	I know what it's like to really not know if I'm going to be here in five years. And something will happen and then I realize that others don't see it the same way. It doesn't hit them. I know what it is to feel alone inside myself.	The woman wrote in her journal, "I feel lonely, it's dark and cold. I feel breast cancer has me running through a maze and there is no light, no sun, and I feel so alone in this. But I know time continues to pass, and I will feel this way from time to time."
Misunderstanding	I have one friend who says to me, "I never think about you as having had cancer because of the way you treated the disease," and I always have to say to her, "But I DID have breast cancer." And if you think that I don't think about it, you're wrong. I do think about it. It isn't that I wasn't affected by it. I told her, "You hurt my feelings when you say that because it tells me you are really not understanding." That makes me feel so lonely because she is one of my best friends.	To convey what loneliness meant, the woman showed a photograph of a woman climbing a mountain, wearing a sizeable backpack. She said, "That is how people see me, as a hero climbing a mountain, but they don't understand that I am also somebody lugging a heavy load."
Inauthentic mirroring	There is a pressure on you to be okay. I even had someone say to me, "You are my hero. You went through all of this and still came to work every day." You know, I see all these Oprah shows, and people are like, yeah, I had breast cancer, and I climbed a mountain, and I raised a billion dollars for breast cancer and of course that is what she did. Everyone does that. It's no big deal what I did. I'm no hero. I felt like a sham. In a way, I was pretending to be the better person she saw.	The woman wrote in her journal, "It is like looking into a mirror and you see a different person than everybody else sees. Then you feel the pressure of living up to what they see."
Fragile vital connections	And every day I think about it. Come hell or high water, I will see my child raised. It's a strange thing to really know you can die. It's like you really know a secret, and it affects how you act, but you are also all alone. It is so lonely.	The woman wrote a story for her children called, "Weeds in Mommy's Garden." Weeds were the metaphor used for cancer as she described her intensified need to connect with and help her children understand what she and they were going through.
Withholding truth	Even with your sister you don't want to frighten her. You know what I'm saying, but there are not many people to whom you can really say, "I am really scared."	The woman noted that lines from a poem by a breast cancer survivor rang true to her experience of loneliness, "Friends keep on calling— / You know they mean well. / But really they'd rather / For you not to tell" (Hjelmstad, 2003, p. 36).

the transcripts to ensure accuracy, writing field notes immediately after interviews, maintaining a reflexive journal to challenge thoughts and assumptions, and documenting discussion of the qualitative researcher group (Streubert Speziale & Carpenter).

Results

Demographic and clinical characteristics of the sample are summarized in Table 2. The study results showed that participants conveyed a unique experience of loneliness that was termed *survivor loneliness*. In keeping with Streubert's (1991) method, participants validated that the formalized description of survivor loneliness (as reflected in this article) was comprehensive and true to their experiences. The essences of that experience include emerging consciousness, transcending time, misunderstanding, inauthentic mirroring, fragile vital connections, and withholding truth. Streubert made a distinction between essence and theme: Essence describes the critical characteristics and facets of an experience (the things that make an experience an experience) and themes are categorization statements (H.J. Streubert Speziale, personal communication, September 23, 2008).

Emerging Consciousness

I feel lonely a lot. There is a moment where it comes, or I just become more aware of it. There could be everybody home in my house and I still feel really alone. Sometimes I can detect the reason; it is the anniversary of my surgery and nobody remembers or I just remember feeling so terrified and alone. I just feel really lonely all over again.

The woman conveyed that loneliness was part of her ongoing experience; it arose from within and led her to examine why it emerged when it did. Her feeling was validated by all the participants, who emphasized that they could become conscious of feeling lonely when they realized that others were not aware of an ongoing aspect of their breast cancer experience (frightened about an upcoming mammogram) or memories of the experience (anniversary of diagnosis). They said that people failed to recognize and comprehend what it was like to survive acute treatment and the long-term aftermath of breast cancer, which led them to become conscious of their loneliness. For some, the experience was intense. One woman described encountering a neighbor with whom she had been close before her diagnosis and treatment. Two years later, as the woman recounted the event in a particularly self-critical way, she welled up in tears.

She did not even know I had breast cancer. I thought she was my friend. I mean, don't people

Table 2. Demographic and Clinical Characteristics of the Sample

Characteristic	n
Age (years)	
Range = 33–74	–
Years following completion of acute treatment	
Range = 1–18	–
Race	
African American	3
Caucasian	10
Marital status	
Married	6
Divorced	6
Never married	1
Had children	
Yes	8
No	5
Education (highest completed)	
High school diploma	2
Associate degree	4
Bachelor's degree	4
Master's degree	3
Socioeconomic status (annual income)	
Declined to answer	1
Less than \$50,000	1
\$50,000–\$99,999	8
\$100,000–150,000	2
More than \$150,000	1
Stage at diagnosis	
Unknown	3
Stage I	7
Stage II	3
History of recurrence	
Yes	3
No	10
Surgical treatment^a	
Lumpectomy	9
Mastectomy	7
Adjuvant treatment^a	
Radiation only	3
Chemotherapy only	3
Combination radiation and chemotherapy	5
Hormonal therapy	6

N = 13

^a Participants could choose multiple responses.

talk? Here I was, basically dropped out of sight for several months and she doesn't care enough to ask for me? I had cancer, not a cold. It just made me conscious of feeling very lonely and like I was stupid to think she was really my friend.

Transcending Time

There are many times I feel very lonely. And, you know, the first year everyone feels sorry for you, calling, and then it slows, and that makes you feel lonely. It's not that they don't care. It's just not top priority anymore, because they don't see you as having any problems. It's like you feel "passed over" and that makes you feel lonely.

Although women clearly pointed out that they did not want others to feel sorry for them, they were consistently surprised when others acted as if the breast cancer experience never happened or treated the experience as “over” following the first year. For participants, the experience was “far from over” because they lived with ongoing reminders and felt changed by it. The women validated that being alone with a reality that others did not share awakened loneliness episodically over time.

Misunderstanding

There are times I am really lonely. My sister loves me but she didn't go through it, and my husband, you know, the same. They just don't understand what I went through and the kinds of things I am afraid of now. And that means they don't understand me.

Participants reported that even their closest confidantes misunderstood how cancer had changed their lives. The thought was especially frightening because participants sometimes feared they were becoming estranged from others, which brought a sense anxiety and loneliness.

After the breast cancer, I just had this lingering fear of dying. And you know what my dear husband told me to soothe me? He said, “Remember, we are Catholic and we believe in Heaven, so it should comfort you to know that if you die, you will go to Heaven.” That didn't comfort the mother of a five-year-old and a nine-year-old! He was so not understanding! I thought, “He does not get this.” Did that make me feel lonely? Yes, lonely and scared.

Inauthentic Mirroring

It is so hard for me to be a part of these fundraisers and walks because I have to be a cheerleader. Yeah, breast cancer made me into a better person, and in some ways it did, but I hate the “rah rah.” I think it changed me in some ways that are better but . . . I just want to be myself and not feel the pressure of living up to someone else's ideals.

Although many of the women did report ways they changed and found benefit in the breast cancer experience, such as a deepened sense of empathy for others, they also validated that they felt pressure to act like a hero (conceal their fears or ongoing symptoms) and sometimes look better than they felt. Even when it did not represent their true experiences, the women reported the pressure in social situations, at work, and with friends and family.

I was at this party and a woman came up to me and said, “I know you are a breast cancer survivor, and you are a bigger hero to me than if you were a movie star.” I almost asked her how on earth I qualified when all I did was take chemo, barf every

day, and lose my hair. What was the alternative? Instead, I just let her see me the way she needed to, but it made me feel bad, not good. I think that goes back to how people see you as a symbol or what they need. That can be a lonely experience because it is not really you.

Fragile Vital Connections

Someone said to me, “This will either make your marriage or make it worse,” and we are still married. I don't know how, but it hurt us.

Participants described how loneliness emerged when they felt a crisis in their connection with others, such as when people were not there for them in ways they expected. They said the breast cancer experience reminded them that everyone is alone in the world in a way—one gets sick alone, undergoes treatment alone, faces mortality alone. Participants reported that they saw life in a light that illuminated how fragile one's connection with the world and with others really is. They said feeling disconnected was complicated for women because women often defined themselves in terms of their connections with others (e.g., mother, wife, friend). The metaphor of a garden came up in many interviews. The participants validated that women are like gardens: fertile environments through which others grow, bloom, and are bound together. One participant added that when cancer invades the garden, it exposes the fragility of women's essential connectedness; all participants affirmed the description. With heightened existential awareness, survivors saw that some of their relationships were less reliable than they had thought and they feared they could not depend on others to be there if they became ill in the future.

When I was undergoing chemotherapy, my husband went away for a week for a training at work. He easily could have put it off. The point is, he did not. That is when I knew, years later, that I really could not depend on him if I got sick again. Did that make me feel lonely? Yes, but at least it was facing up to the truth.

Women described a certain paradox in the breast cancer experience. Although it revealed that life and their attachments to others were fragile, it also illuminated the importance of finding meaning, purpose, and deepened connection with others. All the mothers in the study validated that the crisis of cancer and its threat of disconnection galvanized them to survive so they could raise their children to adulthood.

I made sure my daughter got a secondary education, made sure she was set for college. There was no dallying around. It was important to me that she was set because I did not know how long I would

be around. While I could, I was making sure that she was set.

Moreover, participants affirmed a deepened sense of empathy for the suffering of others. Several women conveyed their intensified sadness about injustice in the world or the tragic loss of life through accident or illness.

I will often be surprised how a disease or accident makes me tear up. The breast cancer made me so cognizant of what people face, and I think those of us who have had this experience really have a specialized knowledge of what suffering means. I think that kind of knowledge can make you feel lonely because most people do not understand that.

Withholding Truth

I suffer from what they call “chemo brain.” My thinking is just not as sharp, and I forget names and numbers that I used to remember. I just do not tell people about that though. And yes, keeping all this to myself makes me feel isolated and lonely at times, but what are people going to do? I do not want them to worry or feel sorry for me.

The participants said that loneliness emerged when a survivor withheld truth. This meant that survivors silenced themselves, masked how they were feeling, or did not share aspects of their experience. They said they were afraid that people would say something that would hurt them or confirm a fear they had not voiced (e.g., “I noticed you are not as mentally sharp.”). When they did not let people know how they were feeling or what they worried about (even if this was to protect others), they felt lonely. The thread that ran through participants’ experiences was that they were afraid to fully reveal themselves to others. Ironically, even in breast cancer support groups, women described the tendency to withhold aspects of their experience. When faced with other survivors, they could silence or chasten themselves for thoughts they characterized as selfish or for an insufficiency of “fighting spirit.” Portraying herself in a support group, one woman said the following.

Everyone said when you got cancer you were supposed to smell, to stop . . . and smell the roses. Well, I just didn’t feel that way. When I met with these other ladies and they said, “Oh I would fight it again and I would fight it again.” I said, “I wouldn’t.” But they said “Oh yes, you would.” And I started to feel guilty because my family needs me. But the truth is I’d be more old. I’d be more fat. Everything would happen again! Then I’d really lose my hair. Then what would I do? I don’t want to fight again. But you can’t say that. You cannot tell the truth, and that can be a little lonely.

Discussion

The results revealed a unique description of loneliness for breast cancer survivors. Participants described how they felt alone in the awareness of mortality and invalidated in the experience of ongoing symptom burden, a changed sense of identity and connection, and an altered threshold for distress that pervaded their long-term experience. The portrayal of survivor loneliness could not be explained by any single, theoretical framework. Although existentialist perspectives reflected some aspects of survivor loneliness, study findings highlighted that the acceptance of aloneness that is the cornerstone of the existential pursuit was experienced differently by participants. The survivors, all of whom were women, suggested a more relational meaning to “self” than was reflected in existentialist literature. The participants’ metaphor of self as a garden may better represent the organic and connected nature of how women viewed themselves and their ongoing growth.

Survivor loneliness was characterized by a paradox: Women strove to accept their personal sense of loneliness and live more authentic, connected, and vital lives even as they withheld truths and participated in inauthentic acts to protect others (e.g., acting like a hero for the sake of others or withholding aspects of one’s experience to protect others). The fact that women sought to accept their loneliness even as they participated in acts that contributed to it can be resolved in light of the relational sense of “self” that survivors used in defining themselves. An inauthentic act preserved a sense of connection and created an impression of normalcy and a condition of hope and optimism, which reassured and positively influenced those relationally connected to the survivor. It was the price survivors were willing to pay when they defined themselves not just as one person but as the totality of their connections with others. Ironically, caring for and protecting others felt more authentic to their true selves than always telling the “truth,” which helped to explain how women could be functioning in their various roles and still feel lonely.

Feminist theories, like existential theories, were valuable for understanding the ways that women enacted behaviors of self-sacrifice, caretaking, and silencing themselves, all contributing to their loneliness (Belenky, Clinchy, Goldberger, & Tarule, 1986; Chodorow, 1979; Gilligan, 1982; Jack, 1991). However, they did not account for much of survivors’ descriptions of not being understood as breast cancer survivors. Cognitive models contributed to understanding loneliness as a mismatch between women’s expectations and their realities but did not reflect survivors’ rich and dimensional descriptions about how life changes following breast cancer. Social needs theories shed light

on experiences of invalidation and isolation but were inadequate for explaining much of the data. Finally, the sociologic perspective of illness narratives contributed to understanding women's experience of loneliness by illuminating the process of socially invalidating and isolating survivors (Frank, 1995) but, likewise, did not address the overall portrait of loneliness and the ways in which women withheld truth out of an ethic of care for others (Gilligan).

The current study was the first nursing study to describe loneliness from the perspective of women. Findings supported the small body of nursing research that identified loneliness following breast cancer. Hoybye et al. (2005) employed multiple methods, including ethnography, case study, and face-to-face and online interviews to describe how social isolation following breast cancer could be overcome through an Internet support group. Women described loneliness in the existential experience of "between moved to or entering a new side of life" (Hoybye et al., p. 216). Although the essence of loneliness as emerging consciousness was not explicitly stated, the descriptions did portray an emerging sense of awareness quite similar to findings of the current study.

Fogel et al. (2002) and Samarel et al. (2002) examined loneliness in conjunction with other variables, including depression, anxiety, stress, and social support using the revised UCLA Loneliness Scale, theoretically based on Weiss's (1973) model of social and emotional loneliness. Illustrating the unique value that qualitative research offers to enrich understanding of phenomena and support knowledge development, the current study focused on loneliness as the central concept itself. The UCLA scale may have measured a diminished sense of intimacy or social support, but women in the current study instantly identified the experience of loneliness as part of breast cancer survivorship. They described a distinct experience of estrangement engendered by a health crisis that was not accounted for by current definitions, preexisting theoretical models, and the instruments upon which they are based. The concept of survivor loneliness is presented here to capture the experience of loneliness for women more than one year following breast cancer.

The study reflected the experience of 13 female breast cancer survivors living in an urban setting and may not be reflective of persons in rural settings or men treated for breast cancer. During the course of the study, the researcher built a strong rapport with participants and some women may have become more aware of their loneliness with time and reflection. Many of the women indicated a sense of relief as they revealed feelings they had not previously put into words and, in this way, the research process may have offered therapeutic benefit. Despite the fact that the sample was small, the narratives were rich and deep. A strength of the study is that

participants were actively involved in the iterative process of constructing the article. They repeatedly echoed that it should be read by everyone who has a connection with a breast cancer survivor.

Implications for Nursing

Education

The findings may be used to help students explore the phenomenon of loneliness from a variety of theoretical perspectives, examine the long-term nature of breast cancer survivorship, and identify additional research questions. In addition, the findings can motivate discussion about how society constructs illness narratives that do not necessarily reflect the experience of patients and inspire debate about the purposes those narratives play. Activities could include student interviews with patients; role-playing; simulations; small group work coding transcripts; student's reading and discussing illness stories; and formal discussion of ethical, ontologic, and existential dimensions.

Practice

The current study underscores the importance of communication skills and the use of empathy in nursing assessment. Nurses' ability to care for patients is predicated on shared understanding about the meaning of illness and treatment and the effect of experience on identity and ongoing life. Although survivor loneliness was experienced by all participants, some women were more self-critical and vulnerable to heightened distress. Through attentive and empathic assessment, clinicians should be alert to the unmet needs of longer-term survivors as well as to the importance of identifying and treating the subgroup of survivors who suffer from more intense emotional turmoil. Therapeutic efforts, such as reflective listening, exploring and validating experience, and investigating avenues to decrease isolation, are needed. For example, the assessment question, "A lot of long-term survivors say that people do not really understand their experience. How have things been for you?" offers permission for the survivor to communicate undisclosed aspects of experience. Sensitive attunement to the survivor's experience may lead to referral for additional treatment and support services. To assist nurses with the development of those clinical skills, grand rounds and clinical supervisory groups could be used as forums in oncology nursing practice settings.

Research

The findings of the current study revealed that loneliness is a vital dimension in the overall experience of breast cancer survivorship. The description of survivor

loneliness, uncovered through qualitative inquiry, exposed a major gap in the literature. Prospective studies are needed to further describe survivor loneliness as well as the variables that predispose some women to more intense psychological distress.

Future research using a grounded theory approach should be used to develop a theory of loneliness following women's breast cancer health crisis and its survivor aftermath. An instrument that measures loneliness in the breast cancer survivor population could then be constructed. Following psychometric testing and validation in the survivorship population, the tool could test loneliness in relation to other variables for breast cancer survivors. In addition, the instrument could be validated in other survivorship populations focusing on women following health crises; this would illuminate the nature of women's loneliness experiences following crises and their aftermath in additional survivor populations. Such a program of research based on women's descriptions and their needs, rather than imposed by theories that fail to capture their experiences and hear their voices, may mitigate isolation. As even more women live with ongoing symptoms

and an awareness of their mortality, treatment should focus more on survivorship. Women's experiences and descriptions of loneliness point out that breast cancer is "far from over" in their lives.

Conclusion

The current study contributes significantly to the breast cancer literature by exploring the experience of loneliness for women a year or more following breast cancer treatment. This is the first study that directly investigated the experience of loneliness for women diagnosed with breast cancer beyond the acute primary diagnosis and treatment phase. The study uncovered new knowledge—a unique description of a new concept, survivor loneliness—that went beyond the current literature in nursing and revealed what was not fully captured by other frameworks.

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Listen in as *Oncology Nursing Forum* Associate Editor Ellen Giarelli, EdD, RN, CRNP, interviews Mary Rosedale, PhD, APRN-BC, NEA-BC, about awareness of mortality and loneliness in breast cancer survivors. Rosedale specializes in women's mental health issues across the lifespan and is involved in the emerging area of novel brain stimulation treatments for psychiatric illness. To listen to the podcast, visit www.ons.org/publications/journals/onf/podcasts.shtml.