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Confronting the Unexpected: Temporal, Situational, and Attributive Dimensions of Distressing Symptom Experience for Breast Cancer Survivors

Mary Rosedale, PhD, APRN-BC, NEA-BC, and Mei R. Fu, RN, ACNS-BC

According to the World Health Organization (WHO), 2005, more than a million people will be diagnosed with breast cancer each year worldwide. Despite the worldwide epidemic, improvements in treatment have substantially increased survival rates, resulting in more than 2.4 million breast cancer survivors in the United States (National Cancer Institute [NCI], 2008) and millions more worldwide. As the number of people living after cancer exponentially rises, discussions about the global burden of disease increasingly focus on cancer (WHO) and how breast cancer and its treatment affect the quality of life of breast cancer survivors (Knobf, 2007; Paim, de Paula Lima, Fu, de Paula Lima, & Casali, 2008). NCI (2006) specifically identifies the need for research with cancer survivors to examine chronic and late effects of cancer and its treatment. The effects of cancer are influenced by women's responses to the traumatic event of cancer, including how they make meaning of cancer and how they perceive ongoing symptoms (Antoni et al., 2001). The ways women perceive and respond to their symptom experiences are vitally important in understanding the long-term effects of breast cancer on survivors (Armstrong, 2003; Budin, Cartwright-Alcares, & Hoskins, 2008).

Uncertainty, feelings of vulnerability, and high levels of emotional distress have been reported in breast cancer survivors in the years after active treatment (Aranda et al., 2005; Budin et al., 2008; Paim et al., 2008). A review of breast cancer survivorship (Knobf, 2007) found that survivors experienced increased psychological distress and worsened health outcomes when they felt unprepared about what to expect in survivorship. That finding was supported by this article's first author's original study, in which all participants described a sense of survivor loneliness and a subset of women described heightened distress (Rosedale, 2009). Although researchers have reported significant prevalence of ongoing symptom experience by

Purpose/Objectives: To describe women's unexpected and distressing symptom experiences after breast cancer treatment.

Research Approach: Qualitative and descriptive.

Setting: Depending upon their preference, participants were interviewed in their homes or in a private office space in a nearby library.

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

Methodologic Approach: Secondary analysis of phenomenologic data (constant comparative method).

Main Research Variables: Breast cancer symptom distress, ongoing symptoms, and unexpected experiences.

Findings: Women described experiences of unexpected and distressing symptoms in the years following breast cancer treatment. Symptoms included pain, loss of energy, impaired limb movement, cognitive disturbance, changed sexual experience, and lymphedema. Four central themes were derived: living with lingering symptoms, confronting unexpected situations, losing precancer being, and feeling like a has-been. Distress intensified when women expected symptoms to disappear but symptoms persisted instead. Increased distress also was associated with sudden and unexpected situations or when symptoms elicited feelings of loss about precancer being and feelings of being a has-been. Findings suggest that symptom distress has temporal, situational, and attributive dimensions.

Conclusions: Breast cancer survivors' perceptions of ongoing and unexpected symptoms have important influences on quality of life. Understanding temporal, situational, and attributive dimensions of symptom distress empowers nurses and healthcare professionals to help breast cancer survivors prepare for subsequent ongoing or unexpected experiences in the years after breast cancer treatment.

Interpretation: Follow-up care for breast cancer survivors should foster dialogue about ways that symptoms might emerge and that unexpected situations might occur. Prospective studies are needed to examine symptom distress in terms of temporal, situational, and attributive dimensions and explore the relationship between symptom distress and psychological distress after breast cancer treatment.

breast cancer survivors (Fu, Axelrod, & Haber, 2008; Paim et al.), little research has examined how women perceive ongoing, unexpected, and distressing symptom experiences. An exception is Knobf (2002), who found increased distress when young women thought of the menopausal symptom experience as “unnatural” and “nonage appropriate,” and when survivors perceived symptoms as disruptive to functioning at home or work.

To shed light on women’s experiences of unexpected and distressing symptoms in the years after active cancer treatment, this qualitative secondary analysis examined how women perceived unexpected and distressing symptom experiences. Re-analysis of phenomenologic data from the first author’s original study on survivor loneliness revealed sufficient information to conduct this secondary data analysis.

Methods

A phenomenology method was used in the original study, which focused on survivor loneliness. In the study, all participants reported that they withheld aspects of their symptom experience to shield others from the reality that they faced even when doing so contributed to their sense of loneliness (Rosedale, 2009). The current study used secondary qualitative analysis to examine the original data set and answer a different question. According to the typology identified by Thorne (1998), this is an example of analytic expansion. Secondary interpretation of the researcher’s own database answers the question, “What are the breast cancer survivors’ experiences of unexpected and distressing symptoms in the years following breast cancer treatment?”

As Thorne (1998) noted, the constant comparative method, interspersing immersion and distance, can be applied to text and support the value of qualitative secondary analysis. With the constant comparative method, the goal of this study was one of discovery and description. “Discovery is defined as the presentation by the researcher of new perspectives on or about the human phenomenon under study” (Kearney, 2001, p. 146). Through discovery of recurring themes and remaining close to the data, a fuller description is provided of how women perceive unexpected and distressing symptom experiences in survivorship. Central to this method is a systematic classification process of text data into fewer content-related themes that share the same meaning (Cavanagh, 1997; Downe-Wamboldt, 1992). This was accomplished by a group of qualitative researchers working with the author throughout the study to examine the data, compare codes, challenge interpretations, and inductively develop themes. Atlas.ti v. 5.0 software was used for coding the data.

Participants

Participants were recruited from a volunteer list at Reach for Recovery, a cancer survivors’ network spon-

sored by the American Cancer Society (ACS). Thirteen English-speaking women, aged 33–74 years, who had completed active treatment for breast cancer 1–18 years prior to the study voluntarily participated. Protection of human subjects as well as sample description were elaborated in the original article (Rosedale, 2009).

Procedure

Following the recommendations of Morgan (1993) and Weber (1990), the first author: (a) read the transcripts several times to gain a broad understanding of the text; (b) met with a group of qualitative researchers who reviewed transcripts, identified key quotations, and discussed key codes related to the research question; (c) combined the coded quotations into one file and confirmed the accuracy of the code and quotation; (d) carefully read quotation files and, with the group, identified major themes by putting key coded quotations together for each research question; (e) met with the group, reviewed major themes, and engaged in active dialogue to resolve any discrepancies; and (f) reviewed the transcripts and validated the structure of themes alongside interview data.

Findings

Participants described their experiences of unexpected and distressing symptoms in the years after breast cancer treatment. Symptoms included pain, loss of energy, impaired limb movement, cognitive disturbance, changed sexual experiences, and lymphedema. The four central themes that were derived from the women’s experiences of ongoing and unexpected symptoms included living with lingering symptoms, confronting unexpected situations, losing precancer being, and feeling like a has-been.

Living With Lingering Symptoms

The diagnosis of breast cancer and its subsequent treatment often were women’s first brush with mortality and first experience of what living with symptoms meant. During treatment, they experienced a variety of symptoms, such as pain, loss of energy, poor memory, and difficulty maintaining concentration. The women were surprised that the symptoms they had experienced during treatment never disappeared but remained part of their lives. Echoing the views of all, one participant said,

It sounds trite, but I thought I was going to get through surgery and then chemo and then it would be over. But it is far from over and I never really expected that.

The women were surprised that they continued experiencing pain, fatigue, impaired limb movement, and poor memory or concentration even years after cancer treatment. The unexpected lingering of symptoms intensified

distress and anxiety when participants expected the symptoms to disappear after cancer treatment but confronted the reality that symptoms continued into subsequent years. Women indicated that ongoing pain not only took them by surprise but also created apprehensions about cancer recurrence, which made some feel hypochondriacal, frequently calling or visiting doctors because of the need for reassurance. This was reflected in the words of the following participant.

I used to run to the doctor and say the cancer is in my bones, I feel it my feet. When you have had cancer, you think your headache is just a different headache from anybody else's. You think everything is related to the cancer.

Some women reported continued cognitive problems such as memory loss, poor memory, or lack of concentration. They described "blanking out," not remembering where they were going, and having problems maintaining concentration. The women who conveyed interruptions in their thinking believed that the ongoing effects were related to chemotherapy treatments.

You know, I never felt like, neurologically, I really returned to my precancer state. I kept thinking it would get better, but it never did. To this day, I can have "blanking out," and my mind is just not sharp like it was.

The experience of loss of energy was profound for many women because they previously had defined themselves as "high-energy" people. Several women were surprised that their energy levels after breast cancer treatment never really returned to precancer baseline. As one of the participants remarked,

I feel anger at the loss of energy. I used to hop on my bike, think about studying for a doctorate, but all that gets disrupted. Everything is disrupted. I get mad because I never knew that I would have to learn to live with this.

Anger and disappointment usually came with the loss of energy. Another participant stated,

Then I found after that I really lost my energy. Really, and I never really got it back. And there is anger at that loss of energy. I was a "do-it-all" person, and now I fall asleep in front of the TV.

Lack of preparation for lingering symptoms resulted from the fact that the women were not counseled or informed to expect symptoms to continue over time. One woman speculated that clinicians withheld information about ongoing symptoms because they did not want to scare women.

I guess they do not want to scare you, but frankly, no one told me that these problems were going to be a part of my life. Quite the contrary, they acted like I just needed to get through treatment and then

things would return to normal. It really bothers me because no one tells you that these things are going to last for a long, long time.

Lack of preparation for lingering symptoms also intensified the women's distress because it led them to question their judgment. They feared that they were bothering their doctors with unreasonable or exaggerated complaints. Women sometimes withheld symptom complaints because they feared that they could negatively influence or even risk the loss of relationships with their doctors. For example, a participant said,

I felt like I was bothering (the doctor), and I didn't want that because if he got sick of me . . . then where would I be? The thing is, you don't know what your new normal is, and you are afraid that every little symptom is cancer again.

Confronting Unexpected Situations

One woman described her sudden encounter with symptoms of lymphedema at a time and in a way that she did not expect. During airplane take-offs and altitude changes, she felt a frightening band of pressure across her chest. The physical sensation of the experience, compounded by the anxiety it produced, was so uncomfortable that she changed jobs to avoid the experience. She said it felt like she was losing control over her body and triggered fears that she would develop a cancer recurrence.

Even when women were counseled and aware of residual effects such as lymphedema, they did not imagine how symptoms might play out in the context of their daily lives. The women offered numerous examples, such as the inability to carry groceries, lift trays of food, or wipe counters. The lack of preparation for such instrumental challenges intensified distress. Distress was compounded when women felt misunderstood or were accused of feigning or exaggerating their symptom experiences. Describing her frustration, one participant, a waitress, conveyed how her boss failed to understand her lymphedema-associated restricted movement.

She made me get a doctor's note. Maybe she thought I was shirking. Nobody understood that you couldn't lift up the tray, you couldn't do things, but nobody understood because you don't have cancer anymore, but you still have the after-effects.

Women noted how limitations were particularly distressing when they had an impact on child care, such as when they were unable to lift a child from the bath or carry a child. One woman reported,

It bothered me so much because I could only pick the baby up if I favored my left side. I had to constantly maneuver myself.

Independence was curtailed in ways such as having difficulty manipulating a steering wheel while driving.

Another participant noted,

No one ever told me that I would have a hard time turning a steering wheel. I never knew I should expect that. Why don't people tell you these things?

Women described feeling unprepared to expect decreased sensation resulting from removal of a breast or nipple, which lessened their sexual arousal. Moreover, many described surprise that vaginal dryness (a consequence of chemotherapy-induced menopause) lessened arousal and enjoyment of intercourse. With the chemical onset of menopause, some women experienced a decreased generalized sensation and lowered sexual desire and worried that their interest in sex would never return. One participant noted,

It never occurred to me that I was going to lose my nipples and that was going to change my sexual experience, and it did, it was huge, I never realized until after the mastectomy what a big part your nipples play in the sexual act. No one ever told me that I was going to have to live with that.

Several women said they were never prepared to expect that their newly constructed breasts would feel hard and "unlifelike." Another woman described,

My breast became really hard. I just didn't want him touching me there, and probably since then we really had no sex life. I don't know if it was because I was put into menopause because of the injections. My body changed, and I had really no desire, not with him, not with anybody. I thought maybe it would get better over time but it never did.

Losing Precancer Being

Living with lingering symptoms and confronting unexpected situations carried additional meaning for how the women viewed themselves. Some women felt a "loss of innocence"; they believed that they would never return to a precancer state in which they could be less somatically focused and anxious. Several women reported that, after breast cancer treatment, they did not feel the same way about their bodies again. This was wistfully portrayed in the words of a participant:

I used to have beautiful hair. Everyone remarked on it. But it never came back the same way. And I look much older now—like I aged overnight. I wasn't like that before. I never would have said it aloud, but I used to see myself as the pretty young mother of two kids. Now, I don't really like my hair, my face, or my body, and it might sound vain, but I mourn the fact that the pretty young mother is gone.

In addition to body-image changes, women sometimes described the sense that their bodies had betrayed them and could no longer be trusted. Other participants noted

a lost sense of self-distinctiveness. This was expressed in descriptions of altered appearance or capabilities. The changes were perceived as carrying a cost to identity. One participant said,

If I had to do it over, I would have let them take the second breast. Now I live with wondering, when is this one (pointing to breast) going to turn on me?

Another woman reported,

I went from being a gym nut, 47, pushing weights, to a chemo patient with thin, flat hair and baggy eyes. And I never completely came back.

The sense of self as a sexual creature was lost in the experiences of diminished sexual arousal, dry vagina, and loss of breasts. However, the women emphasized the importance that their partners continued seeing them as sexually desirable despite their own feelings. One woman said,

It sounds funny to say it, but sex the day I got home from the hospital was a very big plus. It was like, "Yeah, you're still there." And he never stopped seeing me that way.

Another participant said,

I have no feeling. And I always, I thought it would affect my husband, but it never did. He said my breasts felt like two speed bumps. That made me laugh. Sex is not the same, but it is satisfying.

Feeling Like a Has-Been

Several women described feeling that the chief event (having breast cancer) had occurred in their lives and shifted their focus to the past. They described feeling like a has-been. With surprise, they portrayed how their spouses, family members, and friends believed that the cancer experience was over when, in fact, it was enduring. Unexpectedly, physicians no longer provided the vigilant oversight and clinical attention (which characterized the time of acute treatment) and instead could seem annoyed that the women had questions and concerns. Moreover, they indicated that popular discourse about breast cancer survivorship relegated their experiences to the past (that she had "recovered" or "survived" from a past event) even though the experience was ongoing. This contributed to a sense of isolation that women did not anticipate, which was described in the original study as survivor loneliness. Feelings of helplessness arose when women described the unmet need to be seen and affirmed in the reality of their enduring experiences. The feelings were depicted in the words of the one participant.

Seven years out and I'm supposed to . . . I guess I'm an old has-been. . . . Am I? Unless I go for my test at Christmas and I get, found again. Then I'm not a has-been. Then I'm a, oh boy, two-timer. But who wants that?

Discussion

Although lingering symptoms and unexpected situations have been reported (Budin et al., 2008; Fu, 2005; Knobf, 2007; Paim et al., 2008), this secondary data analysis was the first to explore women's experiences of unexpected and distressing symptoms. Breast cancer survivors' perceptions of and responses to unexpected symptom experiences have not been described previously. In this study, as women sought to integrate the cancer experience into their continuing lives, they confronted myriad unexpected challenges for which they felt unprepared. Figure 1 depicts the temporal, situational, and attributive dimensions of symptom distress.

Findings show that the temporal dimension of symptom distress comes from lingering symptoms that the women expected to disappear. The lack of preparation for lingering symptoms intensified the women's emotional responses (distress) to the symptoms. The situational dimension of symptom distress comes from the women's confrontations of unexpected situations evoked by certain symptoms, such as lymphedema. Again, lack of preparation for unexpected situations intensified the distress from the symptoms, which created the unexpected situations.

The attributive dimension of symptom distress is characterized by the themes of losing the precancer being and feeling like a has-been. For the women, the ongoing symptoms and the emotional responses evoked by the symptoms were a reminder that they would never return to their precancer beings. The distress and anxiety were intensified by an important paradox. Women believed that their well-meaning family members, friends, and doctors pressured them to return to their precancer beings, even as ongoing symptoms consistently reminded

the women that they had lost their precancer beings and that they could never return. In an oblique way, doctors sent the same message when they demonstrated little regard for complaints, discouraged discussion of symptom experiences, or treated the women as though they were hypochondriacal. The message was that cancer was over. These findings support research about the survivor experience of feeling pressured to conceal distress and having complaints minimized or dismissed by doctors or family members (Cowley, Heyman, Stanton, & Milner, 2000; Fu, Xu, Liu, & Haber, 2008; Sinding & Gray, 2005; Thomas-MacLean, 2005).

Women reported that they, too, could temporarily forget they had been treated for breast cancer or begin to relegate the experience to the past. However, when they were reminded by symptoms and their own altered responses to occurrences, they no longer could block the conscious awareness that they had changed. They vacillated between relegating the cancer experience to the past and chiding themselves for what one woman described as the "hubris" of believing that the cancer experience was over. Consistently, the women conveyed how they confronted the unexpected situations elicited by the symptoms. The reality was that cancer was far from over. This supports a report produced by the Institute of Medicine and National Research Council (Hewitt, Greenfield, & Stovall, 2006), aptly titled, "From Cancer Patient to Cancer Survivors: Lost in Transition," that highlighted gaps in knowledge and unmet needs of survivors.

Because their altered ways of thinking about themselves and the world were not apparent to others, women indicated that they were not fully seen. The helplessness inherent in this invisibility was highlighted poignantly by one woman who wondered whether she needed to have a cancer recurrence to overcome feeling like a has-been. The experience of not feeling understood and its associated emotional distancing are described in the first author's original article on the experience of survivor loneliness following breast cancer (Rosedale, 2009).

This study was limited because it reflected the experience of the 13 female survivors of breast cancer living in an urban U.S. setting. In industrialized nations, women diagnosed and treated for breast cancer are living longer than ever before. With growing rates of detection and incidence, aging demographics, and advances in treatment, the number of women living with the after-effects of breast cancer treatment continues to rise precipitously (Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2005). However, few studies have examined why some symptom experiences are particularly distressing to longer-term survivors (Ganz, 2005; Ganz et al., 2002; Samarel, Tulman, & Fawcett, 2002). The current findings provide an impetus for other researchers to further explore the phenomenon in terms of temporal, situational, and attributive dimensions.

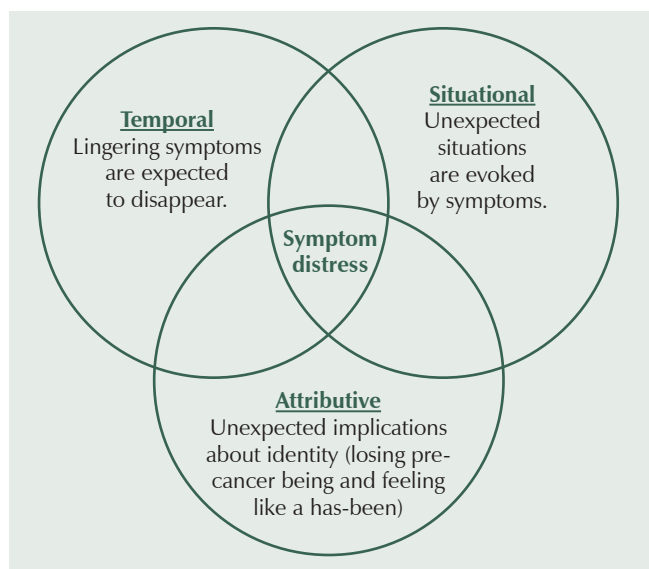


Figure 1. Temporal, Situational, and Attributive Dimensions of Symptom Distress

Nursing Implications

The ways breast cancer survivors perceive ongoing and unexpected symptoms influence their quality of life. Clinicians should explore the needs of women after treatment and examine the process that frames expectations about survivorship. To decrease distress, clinicians should prepare women for the ways symptoms may play out in their lives. Follow-up care should include discussion about the ways that symptoms can emerge, situations that can occur, and how to live with symptoms.

Prospective studies are needed to examine symptom distress in terms of temporal, situational, and attributive dimensions and explore the relationship between symptom distress and psychological distress following breast cancer treatment. Understanding that symptom distress encompasses temporal, situational, and attributive dimensions could help researchers plan more spe-

cific interventions targeting each dimension to decrease symptom distress in breast cancer survivors. In keeping with the goals of WHO (2005), enhanced knowledge about the long-term survivorship and symptom experiences of cancer survivors will affect future trends. Although the data reflected in the qualitative reanalysis presented here reflect perceptions and perspectives from a U.S. sample, the authors hope this article will stimulate global discussion about the lingering symptoms and unexpected situations evoked by symptoms that characterize the longer-term experience of women after breast cancer.

Mary Rosedale, PhD, APRN-BC, NEA-BC, and Mei R. Fu, RN, ACNS-BC, are assistant professors in the College of Nursing at New York University in New York City. No financial relationships to disclose. Rosedale can be reached at mtr3@nyu.edu, with copy to editor at ONFEditor@ons.org. (Submitted November 2008. Accepted for publication March 7, 2009.)

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