

Living in It, Living With It, and Moving on: Dimensions of Meaning During Chemotherapy

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Purpose/Objective: To explore the meanings assigned to the experience of receiving chemotherapy.

Design: Descriptive exploratory.

Setting: An oncology outpatient clinic in a university hospital in Montreal, Quebec, Canada.

Sample: Ten women with breast cancer who experienced chemotherapy for the first time.

Methods: Semistructured interview using a grounded theory approach.

Findings: Women described three dimensions of their experience with breast cancer and chemotherapy: "living in it," "living with it," and "moving on." Existential and situational meanings were an integral part of their experience. The existential meaning seemed to be present in varying degrees of intensity throughout the treatment, whereas the situational meanings were predominant at the beginning of the treatment phase and became less important as the treatment progressed.

Conclusions: The intrapersonal and interpersonal dimensions of the chemotherapy experience as well as the capacity to move on evolve within a context of both situational and existential meanings.

Implications for Nursing Practice: The study results suggest the potential value of exploring each woman's inner world of meanings in relation to her sense of self, relationships with others, resources, and coping strategies during treatment for breast cancer. Because existential and situational meanings are an integral part of women's experience, the nurse's role is to create an environment that permits and facilitates dialogue about these dimensions of meaning.

The incidence of breast cancer has been increasing gradually for the past three decades (Hortobagyi, 1998). The American Cancer Society (2001) estimated that 192,200 new cases of breast cancer would be diagnosed in women in 2001 in the United States, and according to the Canadian Cancer Society (2001), one in nine women would develop breast cancer. Women with breast cancer and their families identified major psychological and physical consequences as a result of the treatments and their side effects (Hilton, 1993). At a time when issues of role identity, the effects of treatment, fear of recurrence, and the possibility of death are at the core of women's experiences, evidence exists that individuals who are able to find meaning in their experiences cope better during the recovery period (Thompson & Janigian, 1988).

Key Points . . .

- ▶ Receiving chemotherapy for breast cancer influences women's perceptions of themselves and their relationships with the people around them.
- ▶ Finding new meanings of both situational and existential natures is an integral part of the experience of receiving chemotherapy.
- ▶ Nurses have a role in creating an environment that permits and facilitates dialogue about meaning.

Literature Review

The Concept of Meaning

The concept of meaning has been presented in the literature from two main perspectives: existential meaning as it relates to the individual's perception of his or her place within the world (Frankl, 1984; Koestenbaum, 1976; Marris, 1974; Patterson, 1988; Thompson & Janigian, 1988; Yalom, 1980) and situational meaning, which is related to how individuals evaluate specific events (Lazarus & Folkman, 1984; McCubbin & McCubbin, 1993; Rolland, 1987; Taylor, 1983; Thompson & Janigian).

Existential meaning: Frankl (1984) viewed the search for meaning as a primary motivational force in humankind. For him, suffering creates a search for meaning that results in a powerful need to make sense of one's life. Yalom (1980) referred to the search for meaning as a search for coherence and purpose in life, whereas Koestenbaum (1976) distinguished between meaning of life and meaning in life. Thompson and Janigian (1988) proposed a framework for understanding the search for meaning based on cognitive representations called life schemes, where a sense of order and purpose regarding the world are key elements. Richer and Ezer (2000) posited

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that existential meaning is determined by past experiences and beliefs and is the individual's global representation of his or her place in the world. Furthermore, finding meaning is a process that has a pervasive impact on many facets of the human experience.

Situational meaning: In contrast to the global, existential views of meaning, Lazarus and Folkman (1984) focused on a different dimension of meaning. They identified two simultaneously occurring cognitive appraisal processes that contribute to the meaning of a specific event or situation. In a primary appraisal, the individual judges a situation as benign, as a potential threat, or as a challenge. In a secondary appraisal, the individual evaluates the personal or external resources available to deal with the situation. Situational meaning also is reflected in Thompson and Janigian's (1988) notion of "implicit meaning" and is comparable to Lazarus and Folkman's concept of cognitive appraisal. Thompson and Janigian defined implicit meaning as the personal significance attached to a negative event that evokes a special set of problems and emotions that affect the adjustment process. The literature increasingly suggests that conceptual distinctions need to be made between these two dimensions of meaning (Richer & Ezer, 2000; Thompson & Janigian) and that the differences have implications for clinical practice as well as research.

Meaning of Cancer

Although a number of studies have addressed the importance of meaning in the cancer experience, only a few authors have explored a conceptualization of meaning that included both existential and situational dimensions. O'Connor, Wicker, and Germino (1990) interviewed patients newly diagnosed with cancer and found six major existential themes involved in each person's search for meaning after a diagnosis of cancer. They also described situational meaning as an individual's perception of the impact of the cancer diagnosis on daily activities. Fife (1994) examined two dimensions of meaning: self-meaning and contextual meaning. She described self-meaning as the perceived effect of an event on the individual's identity and contextual meaning as the perceived characteristics of the event and the social circumstances around it. Fife concluded that the meanings that people associate with their illness and its treatments could serve as clinical markers and provide some indication of the quality of the adaptation those individuals will be able to make.

The Meaning of Chemotherapy Treatments

The studies that examine the meaning of chemotherapy treatments mainly have focused on situational meanings. In a study of the meaning of chemotherapy treatments among patients treated for malignant lymphoma, Nerenz, Leventhal, and Love (1982) found that vague, diffuse side effects, such as fatigue and pain, cause more distress than acute, specific side effects like nausea and vomiting. Weekes and Kagan (1994) attempted to include both situational and existential meanings in their description of adolescents undergoing cancer therapy and identified the themes of task accomplishment and movement toward a normal life in their experience. Although these studies focused on the meaning of receiving chemotherapy, none were found that addressed the meaning of the experience for women undergoing chemotherapy for breast cancer.

The purpose of this study was to explore the meanings assigned to the experience of receiving chemotherapy among

women recently diagnosed with breast cancer. To identify the concepts associated with this phenomenon, the following questions were addressed: What is the impact of the disease and the chemotherapy treatments on women's physical well-being, on their emotional state, and on their social relationships? What type of meanings do women assign to their experience?

Methods

Design

A descriptive exploratory design was selected to allow for in-depth examinations of the women's experiences. The grounded theory approach was chosen to allow for the discovery of concepts that were not clearly identified in the literature, to describe the relationships between these concepts, and to document how they evolve over time (Morse & Field, 1995).

Sample

Initial inquiry began as part of advanced clinical practice in the field of oncology. To describe the full nature of the phenomenon, women in an oncology clinic at different points in time during the course of chemotherapy treatments were selected for participation in the study. Participation was voluntary, and women agreed to be interviewed at each of their clinical visits until they received their last chemotherapy treatment. To be included in the study, participants had to be receiving chemotherapy for the first time and agree to share their experience in an ongoing basis over the remaining course of treatment. Women from diverse cultural and socioeconomic backgrounds were included to provide different perspectives. According to Sandelowski (1986), including people of diverse backgrounds helps to avoid the possibility of elite bias in which only the most articulate, who tend to be of higher socioeconomic status and members of the dominant culture, are represented. Women who had other cancers diagnosed in the past were excluded from this study.

Procedure

Data were collected using semistructured interviews that were transcribed immediately and reviewed. During data analysis, transcripts were reviewed and tentative themes were highlighted. Common concepts that emerged from the data were identified and labeled. As the data collection and analysis progressed, questions became more focused to explore these concepts with the participants in the study. Concepts then were grouped into categories, and categories were grouped into dimensions. Interviewing and recruiting new participants continued until no new themes emerged from the data and the categories were saturated. Interviews lasted 25–75 minutes with the average interview lasting approximately one hour. Fifty-five interviews were conducted, with an average of 5.6 interviews per participant.

Validity and Reliability

The categories identified from the data were verified with the participants in later interviews, thus establishing credibility through corroboration. Colleagues and the research team addressed inter-rater reliability by reading the data and confirming that the emerging themes were representative of the raw information. The categories were discussed with and corroborated by nurses in the oncology clinic.

Findings

Ten women who met the study criteria were interviewed (see Table 1). The women ranged in age from 44–69 years (\bar{X} = 55.9 years). Seven women had undergone lumpectomy or a partial mastectomy prior to their first course of chemotherapy, whereas three went on to have their surgery after the completion of chemotherapy. Eight women received six cycles of treatment, one woman received four cycles, and another woman was transferred to palliative care to continue her treatments because of extensive metastases.

The experience of receiving chemotherapy for women being treated for breast cancer is a process that evolves over time. As shown in Figure 1, three major dimensions emerged from the data: living in it, living with it, and moving on. Women described the impact of chemotherapy treatments on both their inner worlds and their relationships with people in the world around them. Each of the three dimensions included three categories. Living in it reflected the intrapersonal dimension of the experience and included “side effects make the cancer real,” “my body: friend or foe,” and “applying things learned in the past.” Living with it reflected the interpersonal dimension and included “sparing the family,” “unwanted sympathies,” and “my life around the clinic.” Moving on reflected the reconciliation with one’s life in light of the chemotherapy and cancer experience and consisted of “seeking a new balance,” “making plans,” and “back to normal.” The data also suggested that women used two types of coping

strategies to move between the three major dimensions of the cancer experience. These categories were part of the process called “getting there” and included “put it aside” and “life lines.”

Throughout the course of chemotherapy, the women’s attribution of both existential and situational meanings was an integral part of their experience. The existential meaning, or the women’s need to make sense of the world and their lives, seemed to be present to varying degrees throughout the treatment period. However, the situational meanings, or the women’s perception of and capacity to handle the immediate consequences of the treatment, were more salient at the beginning of the treatment phase and became less important as the treatment progressed.

Living in It

Occurring inside a person’s mind, living in it represents the intrapersonal dimension that includes the cognitive and emotional processing of the experience of having cancer and receiving chemotherapy. This dimension consists of three categories.

Side effects make the cancer real: This category describes the impact of the side effects of chemotherapy and how the women dealt with them. This was the most important element of the intrapersonal dimension and is at the core of the women’s preoccupation, especially at the beginning of the treatments. Even if the nurses and the physician generally informed women about possible side effects, most expressed astonishment at how much this affected them. Some women thought it was going to be worse; some thought it would be easier. All of the women experienced side effects that included fatigue, hair loss, gastric discomfort, alteration of taste, and decreased sexual activity because of changes in the vaginal mucosa. Of the 10 informants, six lost all of their hair and all of the women had intense reactions to this loss. One woman wondered how she would handle her loss of hair.

When I first lost my hair, I put it into a bag; I couldn’t bring myself to throw the bag in the garbage. My doctor had not made it clear at the beginning that I was going to lose my hair. At the time, I was really wondering how I was going to handle it; I’ve always been so proud of my long hair. You know for a woman, her hair is like her crowning glory. It was very difficult for me . . . I miss letting down my French twist at night and passing my hands in my hair, brushing it. I took great pride in my beautiful long and thick hair. . . .

Furthermore, the hair loss was a constant reminder of the illness experience. Another woman said the following.

When my wig is off, I look at myself in the mirror and I think ‘cancer’ . . . it makes me think that I really have cancer.

My body: Friend or foe? Women expressed ambivalence about their bodies. They considered the body on the one hand as a friend, as they described their desire to do whatever was possible to put their body “back on track.” At the same time, they saw it as an enemy because they felt that their body had “let them down” and the cancer might return. Some women wondered whether the cancer could have been discovered earlier if they had paid more attention to their bodies or had been more vigilant to the changes in their physical state or the

Table 1. Sample Characteristics

Characteristic	n
Stage of breast cancer	
• I	1
• II	5
• III	2
• IV	2
Treatment regimen	
• Doxorubicin + cyclophosphamide	2
• Doxorubicin + docetaxel + cyclophosphamide + neupogen	3
• Cyclophosphamide + methotrexate + 5-fluorouracil	3
• Paclitaxel	1
• Paclitaxel + trastuzumab	1
Sequence of treatments	
• Surgery + chemotherapy + radiotherapy	7
• Chemotherapy + radiotherapy + surgery	3
Ethnic origin	
• French Canadian	3
• English Canadian	6
• Inuit	1
Employment status	
• Retired	3
• Full-time	3
• Part-time	2
• Unemployed	2
Marital status	
• Married	8
• Divorced	2

N = 10

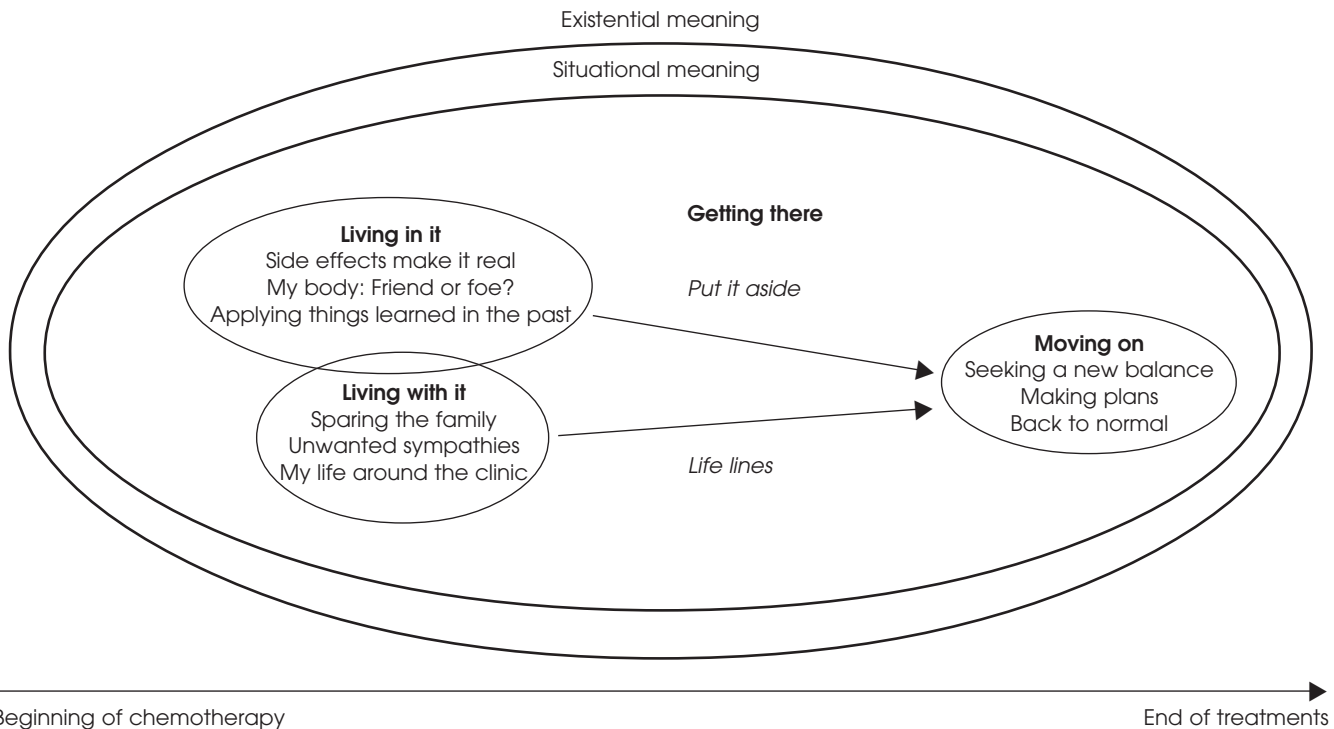


Figure 1. The Experience of Chemotherapy for Breast Cancer: Its Dimensions and the Context of Meaning

appearance of symptoms. Furthermore, any changes in their physical state over the course of the treatment would invariably trigger the fear of recurrence.

I need to go for a bone scan. I have been worried because I have back pains and I think that maybe the cancer is back. It is scary and I don't want to dwell on it, but I need to act on it fast this time, and be realistic.

Applying things learned in the past: Women's past experiences with cancer and other traumatic events also had an impact on how they dealt with their disease and the chemotherapy. One woman described how applying strategies she had learned during previous experiences helped her to cope with her present situation.

My mother never received treatments for her breast cancer and died two years after she was diagnosed. She refused to talk to us about it. I always felt that my mother had isolated herself and didn't take advantage of the treatments that were offered to her. . . . In a way, my mother's experience with cancer has prepared me and my family for what I am living today. I involve my family in my treatment decisions, and I make sure that I keep the lines of communication open.

Four women who had gone through a separation, a divorce, or the death of a loved one also recounted that they felt they were able to use some of the coping strategies they had used in the past to deal with their current situation.

Living With It

Living with it represents the interpersonal dimension related to the experience of receiving chemotherapy. This included the relationships between the women and the people in

their environment, as well as how they felt about the impact of the disease and treatments on others. Three categories were identified in this dimension.

Sparing the family: The impact on the family is by far the most important category of this dimension. Women with children seemed to be particularly worried about the impact of their cancer and the chemotherapy on their families, and they felt a strong need to protect them. Of the seven women who had children, all expressed deep concern about the way that their children responded to the disease and its treatments.

The worst part of my experience with the chemotherapy is to explain it to my 10-year-old son. He worries about me . . . sometimes I find him standing beside my bed in the middle of the night, he looks at me and asks me if I am okay. He has been very disturbed by all this.

Feelings of protection toward family members were reflected in the observation that although eight of the women lived with their spouses, only three husbands stayed with their wives during the treatments. When this was explored, the women said that even when their husbands offered to stay, the women refused because they felt that the process of receiving the treatments was too long. The women did not want their husbands to have to "suffer" through the experience.

Unwanted sympathies: This category reflects the women's difficulties in dealing with the ways in which neighbors or distant relatives interacted with them about the experience of having cancer and receiving chemotherapy. Six of the 10 women interviewed indicated that dealing with the perception of others was especially difficult at the onset of treatment. Women had to deal with questions about treatments and their physical or emotional states at a time when they wanted to

“put it aside” and not think about the cancer for a while. Those women who found the phone calls or visits disturbing isolated themselves and cut contacts with people in their environment whom they felt had the tendency to think of them as “half dead.” One woman explained.

People around me are really getting on my nerves; they talk to me like I am about to die. I can't stand it! My neighbor keeps on bringing me food. I really hate the pitying; I want to be treated normally.

My life around the clinic: Most women receiving chemotherapy came to the oncology clinic at least once every three weeks. Although some women considered going to the hospital as “part of the package,” most found that the time spent in the hospital receiving treatments was difficult and felt that their lives were revolving around their monthly visits. Six of the 10 women expressed dissatisfaction regarding the waiting time prior to chemotherapy. While in the waiting room, women shared their experiences with other patients.

It is difficult to wait; it makes you think more about the cancer, and everyone is here because of cancer . . . so we talk about cancer. The longer we wait, the more difficult it is.

Women also found that they compared themselves to others in the waiting room. One respondent said that she could notice women getting worse from week to week and found herself comparing her loss of hair or her general appearance to that of other women. Some women made it a point to “get busy” in the waiting room by putting some order to a pile of magazines so that they were not available to talk with others.

All of the women interviewed found that the nurses and volunteers were kind to them and they felt that they were treated as “real” people. Many mentioned the smiling faces. The nurses provided them with information regarding treatments, possible side effects, and the best way to manage them. Women found that they received sufficient information but felt overwhelmed by the amount of detail they received, especially before their first chemotherapy treatment.

Three of the women interviewed remarked that although they understood that the nurses were very busy, they felt a strong need to talk about their emotions regarding their cancer and the treatments. These women found it difficult to share their true feelings with their families and friends.

You know I can't really talk to my husband because I can feel that he is very distressed about my condition, and I don't want to upset him. I am really scared about my cancer, and it is a relief that I can talk to a nurse about things that I would not be able to tell anyone else.

Getting There

The women used two types of strategies to cope with their experience and continue with their lives. The “put it aside” strategy was related to the intrapersonal dimension, whereas the “life lines” strategy was associated with the interpersonal dimension.

Put it aside: During their chemotherapy treatments, women described their attempts to bring a sense of normalcy to their lives by trying not to focus or think too much about the cancer. The absence of side effects helped the women to put them aside. One woman described this.

One week after receiving my chemotherapy, I have my ‘freedom week’ when I have no side effects; I can eat what I want and do as I please; it really makes me forget about my cancer.

Another woman confided that by staying busy, she was able to get some relief from the painful and difficult emotions that the cancer elicited.

Life lines: Women mobilized resources to deal with their experience. From the interpersonal perspective, women found support from their families, friends, and communities. They described this type of support as a “life line” that helped them come to terms with their experience. One woman described how the presence of her daughter made all the difference when she had to choose a wig. Another respondent described her husband as her chauffeur, doctor, and psychologist. A woman who exercised regularly found support from her badminton group.

When I go, they encourage me and tell me that I look good. I even learned that two of the women had breast cancer in the past. I was surprised and also encouraged seeing them so healthy and full of energy.

Depicted as soldiers, helpers, and protectors, women described their close family and friends as constant support providers throughout their experience.

Moving on

Moving on represented the phase when women started to face their future. They sought to reconcile their lives and experience with cancer and chemotherapy by seeking a new balance, making plans, and bringing back normalcy in their lives. Women explained that they had to finish all of their cancer treatments before they were able to get to the phase of moving on with their lives.

Seeking a new balance: All of the women said that they spent a lot of time thinking about their lives, their children, their accomplishments and failures, and “how it all fits” in their existence. In reviewing her life, one woman could not believe that it took an experience like cancer to make her reassess her priorities. She described being focused on material things and said that she had not stopped very often to assess her emotional world. This review made her reconsider the meanings that she gave to her existence and led her to seek balance in her life. Other women focused on their achievements.

I lived a good life, I have good children, my husband is very supportive, and I used to do work that I loved. This is important to me.

As they spoke about this self-examination, the women described focusing on their immediate day-to-day experiences and living day by day to make every second count.

Making plans: As the treatment progressed, women slowly began to make plans for the future. Some planned their return to work with major changes in their workloads and schedules, while others looked forward to organizing activities with their husbands. Making plans helped to crystallize the new meaning that women gave to their lives. With one cycle of chemotherapy to go, one woman could not wait to finish her treatments.

My life has been centered around coming to the clinic. I will finally be able to do other things that I always took for granted like going to the flea market and doing all kinds of fun stuff.

Back to normal: Once the treatments were over, women began to reconstruct their “normal” world in light of their illness experience. Some of the attempts that women made to find new existential meaning in their lives were reflected in their attempts to reconstruct or resume their daily activities. One woman who lived alone, wanted to return to her normal routine and her job to regain the control of her life.

I felt very appreciated at work and it is difficult to stay home all day. I am looking forward to getting back to normal, making money, and seeing the people I worked with.

For her, work represented a return to financial independence and control of her future.

Meaning: The Context of the Experience

Chemotherapy had an impact on the women at many levels—on their own physical and psychological states, relationships with others around them, and attempts to handle the disease and move on with their lives. All of these experiences occurred within a two-dimensional context of meaning during which women tried to understand and handle the events as they unfolded, while at the same time reexamining and redefining themselves and their purpose in life. Both existential and situational meanings were present throughout the experience of receiving chemotherapy and were critical elements in the women’s overall experiences.

The situational dimension of meaning was different for each woman and was particularly important at the onset of treatment. For one woman, having gastric discomfort for three days after her chemotherapy meant that her husband needed to cook her meals; for another, irritation of the vaginal mucosa meant a reduction in her sexual activities; and for a third, increased fatigue meant that she had to stop working. Another woman shared her feelings.

Because of the chemotherapy, I had to change things in my life—my eating habits and planning my days around coming to the clinic. You know, I had to handle it and I found ways to do it.

Women found that dealing with the side effects of chemotherapy forced them to come face-to-face with their disease, whereas the absence of side effects allowed them to put their experience aside for awhile.

The existential dimension of meaning also was part of the chemotherapy experience. For some women, it was an issue right from the outset, and for others, it became more important as the side effects stabilized and the women adjusted to the treatment schedule. One woman explained that she did not really believe that she had cancer until she started her chemotherapy treatments. Even after her lumpectomy, she still hoped that the doctors had made a mistake. However, the treatments forced her to face the cancer and make sense of and give purpose to her life.

As they experienced physical effects of treatment or saw the concern of their family members, the women were faced with the realization that the disease might come back. This potential for recurrence raised questions of an existential nature.

My experience with cancer and chemotherapy made me deal with questions about death, life, and disease. We never had to deal with something like this before; we

were more focused on things to do with the material aspects of life. We don’t focus on little things anymore. We learn to live in the moment.

Discussion and Implications for Practice

The findings in this study suggest that the experience of receiving chemotherapy influenced the women’s perceptions of themselves and their relationships with people in their environment. Although pharmacologic interventions have achieved better management of side effects, women expressed both physical and emotional symptom-related distress from the onset of treatments, and for some, this continued after the treatments were over. Other studies (Christman, 1990; Ehlke, 1988; McCorkle, 1987) have suggested that distress resulting from symptoms and side effects of breast cancer treatments were critical factors in emotional and social adjustment. In addition, the chemotherapy treatments had an impact on the women’s perceptions of their roles as spouses and mothers and on their relationships with people around them. This is consistent with Burman and Weinert’s (1997) suggestion that women experiencing cancer were more likely than men to report relationship problems and feel that they were not understood by the people around them. In a secondary analysis of patients receiving cancer treatments, Dibble, Padilla, Dodd, and Miaskowski (1998) found that the most important factor in the quality of life for women experiencing cancer was their psychosocial well-being in relation to others in their environment.

The positive and negative consequences of close social relationships expressed by women in this study have been noted in other studies. Mishel and Braden (1987) found that during treatments, the support that women received from people around them helped to reduce their perception of a lack of control and to focus their attention on the positive aspects of their situation. Lugton (1997) determined that women treated for breast cancer wanted to be treated normally by their neighbors and co-workers. In another study, behaviors that were intended to be supportive may be seen as helpful or unhelpful depending on whether they had been provided at the “right” or “wrong” time for the recipient (Jacobson, 1986). Together, these studies indicate that the timing of support is an important determinant of whether it will be perceived as helpful.

Most studies of meaning during the experience of cancer have combined its existential and situational dimensions. The findings here suggest the importance of considering the dimensions of meaning separately. For the women in this study, the situational meanings of the effects of chemotherapy were especially important at the onset of treatment. Existential meaning also was important, but for some, it did not become salient until the treatments and physical symptoms had stabilized. The need to put the illness aside that was described by the respondents in the study suggests that grappling with meaning is a process that evolves over time and is shaped by the women’s past experiences as well as by the treatment trajectory.

The variation in disease severity, differences in probability of recurrence, the occurrence of metastases among some women in the study, and the small sample size make generalizing difficult. However, the study results suggest the importance of exploring in an ongoing way throughout the course of treatment the women’s inner world of meanings, the physi-

cal experiences, their relationships with others, and their resources and coping strategies. The findings indicate that interventions must be tailored to fit each woman's experience as she moves through the process of finding meaning and adjusting to the illness (Gottlieb & Ezer, 1997; Gottlieb & Rowat, 1987).

The nurse must create an environment that permits and facilitates a dialogue about both of these dimensions of meaning. Nursing interventions that directly address situational meaning include giving information about the disease and treatments that will help the women feel in control of the situation; exploring specific concerns about hair loss, fatigue, or nausea during chemotherapy; and exploring alternatives that mitigate the impact of illness and the treatments on day-to-day activities. Generally, nurses recognize the importance of addressing these issues. However, the more global impact of the illness on an individual's identity and purpose in life is over-

looked or neglected more easily, particularly in busy oncology departments. Nurses need to look for the appropriate time to raise these issues and create a climate of acceptance and legitimacy that will allow patients to share their existential concerns. Having cancer and receiving chemotherapy treatments are experiences that are likely to stay with most individuals. By helping women attach meaning to their experiences, nurses can better prepare them to adjust not only to a diagnosis and its treatments but also to the changes they will continue to experience in the future.

The author dedicates this article to the memory of a good friend, Guilda Abraham.

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