Comparisons Between Cancer Survivors and Family Members on Meaning of the Illness and Family Quality of Life

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Purpose/Objectives: To explore the meaning of the illness to the family and family quality of life (QOL) for survivors and family members and to describe similarities and differences between survivors' and family members' meaning of the illness and family QOL.

Research Approach: Descriptive, qualitative.

Setting: Homes of survivors and family members in an urban metropolitan area in the midwestern United States.

Participants: A sample of 123 Caucasian and African American cancer survivors, one to six years after treatment had ended, and their family members (N = 246). Four cancer diagnoses (i.e., breast, colon, prostate, and uterine) were represented.

Methodologic Approach: Two open-ended questions derived from a family model of survivorship. Content analysis was used to analyze the responses.

Main Research Variables: Meaning of the illness and family QOL.

Findings: The positive dimensions of survivorship in meaning of the illness and family QOL were seen for patients and family members, although long-term stressors also were reported. More similarities than differences in meaning and QOL were noted between survivors and family members.

Conclusions: Patients' and family members' perspectives of the meaning of the illness and family QOL are important to assess during survivorship to address both individual- and family-level perspectives in cancer care.

Implications for Nursing: Nurses should offer opportunities for patients and family members to search for positive meaning in the cancer illness, develop strategies to handle stressors that are present during survivorship, and enhance family strengths and resources to promote family QOL.

Key Points . . .

- Meaning of the illness and family quality of life identified by patients and family members show positive dimensions (e.g., increased valuing of life and family relationships, emphasis on health promotion, early detection) and ongoing concerns (e.g., having cancer in the family, fear of recurrence).
- Meaning of the illness has significance at both individual and family levels and is interrelated closely with family quality of life.
- Cancer survivors emphasized the importance of receiving support from others, whereas family members viewed support as showing concern and giving support to the patients.
- Further research on family survivorship is needed to explore the relationships between meaning and quality of life over time, family communication and coping strategies that promote quality of life, and the chronic stressors of survivorship.

Cancer survivorship, which begins at the time of diagnosis and continues throughout the remainder of life (Mullan, 1996), is critical to address as individuals continue to live years beyond their cancer diagnosis and treatment (Dow, Ferrell, Haberman, & Eaton, 1999; Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995; Ganz et al., 1996). Families experience the cancer illness with survivors, and strong support is evident in the literature for including family members when planning cancer treatment (Davis-Ali, Chesler, & Chesney, 1993; Lewis & Hammond, 1992; Morse & Fife, 1998; Northouse, Mood, Templin, Mellon, & George, 2000). However, a scarcity of research exists about family members during an extended survivor phase.

Major stressful events, such as a cancer illness, are influenced by the meaning that individuals and family members give to them. Although the meaning of the illness has been addressed with cancer survivors (Carter, 1993; Nelson, 1996; O'Connor, Wicker, & Germino, 1990; Taylor, 2000; Utley, 1999), few studies have examined the meaning of the illness to family members (Germino, Fife, & Funk, 1995; Hilton, 1996; Thorne, 1985; Wilson & Morse, 1991). In the past decade, quality of life (QOL) also has emerged as a critical outcome in cancer research (Aaronson et al., 1991; King et al., 1997). QOL is viewed as a subjective concept that is multidimensional and dynamic over time (Cella, 1994; King, 1998). Emphasis has been placed on individual QOL, but few studies have addressed the QOL of family members during the survivorship period.

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Therefore, the purposes of the current study were to (a) explore the meaning of the cancer illness to families and family QOL for cancer survivors and family members, and (b) describe the similarities and differences between the cancer survivors' and family members' meaning of the illness and family QOL.

Literature Review

Meaning of the Cancer Illness

As individuals with cancer continue to survive longer, their search for meaning of the illness has received increasing attention in the literature. The search for meaning has been conceptualized as a process that involves cognitive appraisals, reappraisals, and attributions that individuals make in response to stressful experiences (Park & Folkman, 1997). Numerous qualitative studies have reported the multidimensionality of the meaning of cancer for individual patients. Initially, the search for meaning may include attempting to understand the personal significance of the cancer (O'Connor et al., 1990), interpreting the diagnosis (Carter, 1993), living with the cancer (O'Connor et al.), having hope (O'Connor et al.), and living with uncertainty (Nelson, 1996).

The search for meaning of the illness also is a process that changes over time and may involve several stages (Carter, 1993; Taylor, 2000). Positive aspects of the meaning of the illness for long-term survivors include a new attitude and appreciation of life (Dow et al., 1999; Utley, 1999), more concern for others (Fredette, 1995), greater appreciation of family support (Dow et al., 1999; Fredette; O'Connor et al., 1990), a new sense of wholeness after cancer (Dow et al., 1999; Taylor), and a reevaluation of priorities in life (Fredette; Taylor). However, negative aspects of the meaning of the illness include the view of cancer as multiple losses (Dow et al., 1999), sickness, and death (Utley); abandonment by healthcare professionals (Pelusi, 1997); and seeing the disease as an obstacle to overcome (Utley).

Although the meaning of living with cancer also occurs in the context of the family (Lewis, 1993; Stetz, 1998), only a few studies have addressed the meaning of the illness to family members. Some of these findings have indicated that the meaning for family members involves uncertainty about patients' future and fear of losing their partners (Germino et al., 1995), changes in intimacy and relationships with patients (Germino et al.), attempts to maintain normalcy in family life (Hilton, 1996; Thorne, 1985), supporting patients and keeping a positive attitude (Thorne; Wilson & Morse, 1991), balancing daily living with illness demands (Germino et al.; Lewis & Deal, 1995), minimizing and not talking about the cancer, and putting the cancer behind them (Hilton).

Quality of Life

QOL is a critical dimension in survivorship and has received increasing attention in the literature (Dow et al., 1999; Ferrell et al., 1995; King et al., 1997). Attention to the entire family's QOL also is acknowledged as an important consideration in survivorship (Gotay & Muraoka, 1998; Stetz, 1998). The positive aspects of cancer survivors' QOL include greater appreciation of life (Bush, Haberman, Donaldson, & Sullivan, 1995; Dow et al., 1999; Ersek, Ferrell, Dow, & Melancon, 1997; Wyatt & Friedman, 1996), improved interpersonal relationships (Ferrans, 1994; Ferrell et al., 1995), enhanced spirituality (Ferrans; Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998a), and healthier lifestyle (Ersek et al.). In contrast, the negative aspects of QOL involve uncertainty and fear of the future (Ersek et al.; Ferrell et al., 1995, 1998a; Fredette, 1995), lingering long-term effects of cancer treatments (Dow, Ferrell, Leigh, Ly, & Gulasekaram, 1996; Zebrack, 2000b), altered sexuality and self-image (Ersek et al.; Ganz et al., 1996), economic problems (Ferrans; Ferrell et al., 1998b), communication difficulties with their partners (Ganz et al.), and family distress (Ersek et al.; Ferrell et al., 1995; 1998b).

Research on the QOL of family members has examined adjustment, adaptation, or distress predominantly during initial diagnosis and treatment, the first year to 18 months after diagnosis, recurrence, or advanced stage of the disease. Some research studies have indicated that spouses report increased distress and adjustment problems as the disease progresses (Morse & Fife, 1998), greater distress than the person with cancer (Given & Given, 1992; Kornblith, Herr, Ofman, Scher, & Holland, 1994; Northouse et al., 2000), lower levels of family functioning (Northouse et al., 2000), less social support (Davis-Ali et al., 1993; Northouse et al., 2000), and greater worry about recurrence than the patient (Davis-Ali et al.; Northouse, Laten, & Reddy, 1995). However, other researchers have reported similarities between family members and patients in levels of distress (Baider, Koch, Esacson, & De-Nour, 1998; Northouse, 1989; Zacharias, Gilg, & Foxall, 1994) or patients reporting more role problems (Northouse), greater emotional distress (Northouse, Templin, Mood, & Oberst, 1998), and more sexuality concerns than spouses (Kornblith et al.).

The literature review demonstrates the need to investigate the meaning of the illness and QOL for cancer survivors and family members. Some research has reported that meaning appears to be an important factor in determining cancer survivors' QOL (Dow et al., 1999; Germino et al., 1995; Taylor, 2000; Zebrack, 2000b). Research also has suggested refining the theoretical linkages between meaning and QOL (King et al., 1997). However, minimal attention has been directed to the meaning of the illness and QOL from the perspectives of family members during an extended survivorship period. Furthermore, no studies were found that examined similarities and differences between survivors' and their family members' meaning of the cancer illness and perception of family QOL.

Conceptual Framework

A Family Survivorship Model (see Figure 1), based on the work of McCubbin and McCubbin (1996), guided this qualitative study, which was part of a larger study that tested the model (Mellon & Northouse, 2001). The model contains illness survival stressors (i.e., concurrent family stressors, somatic concerns, and fear of recurrence) and family resources (i.e., family social support and family hardiness) as antecedents, family meaning as a mediator, and family QOL as the outcome. The current study focused on only two parts of the model: family meaning and family QOL. Meaning was defined as survivors' and family members' appraisals of the meaning of the cancer illness to the family, and QOL was defined as survivors' and family members' satisfaction with multiple aspects of their family life. This study specifically described these two parts of the model and examined the similarities and

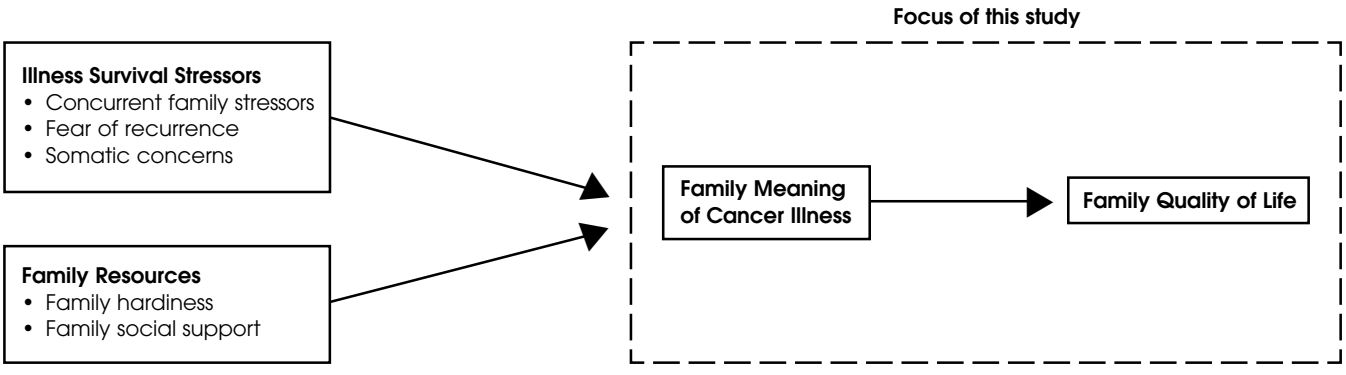

Figure 1. Family Survivorship Model

differences between cancer survivors' and family members' meaning of the illness to the family and family QOL.

Methodology

Design

A qualitative, descriptive design was used for this study. Two open-ended questions, derived from the conceptual framework, were asked of each cancer survivor and family member: How would you describe the meaning of the cancer illness to your family? How do you think the cancer illness has affected your family QOL?

Sample

A stratified (by diagnosis and ethnicity), random sample of 123 family dyads (N = 246) was obtained through a SEER (Surveillance, Epidemology, and End Results) Cancer Registry database in the midwestern United States. The sample consisted of 62 Caucasian family dyads and 61 African American family dyads. Inclusion criteria for the study specified survivors who had been diagnosed one to five years ago, had completed the primary treatment at least one year prior to the study, had cancer diagnoses in stages I–III, were not in a recurrent or terminal stage of the illness, and were not undergoing treatment.

Data Collection and Analysis Procedures

Institutional review board approval was received prior to the start of the study. Individuals and their family members were interviewed together in their homes. Informed consent was obtained prior to the start of the interviews. After a series of standardized questionnaires were completed as part of the larger study, which took less than one hour to complete, cancer survivors and their family members were asked to respond to the two open-ended questions. Verbal responses were written down by the investigators and validated by the subjects. Content analysis following guidelines of data coding, reduction, display, and conclusion drawing (Miles & Huberman, 1994) was used to identify themes for each of the open-ended questions. Each response from patients and their family members was analyzed as a distinct entry under each question. Sentences, phrases, or single words were used in coding for identification of themes.

For reliability of coding, a consultant in qualitative methodology open-coded all data texts. A comparison of coding categories then was completed with the principal investigator, resulting in an interrater reliability of 96%. Subsequent discussion led to consensual agreement for the final coding of the qualitative data. Following the study's purpose, themes were organized under the categories of similarities and differences between survivors and family members in meaning of the illness and family QOL. During analysis, several themes were identified that overlapped in similarities of meaning and QOL. Subsequently, themes were reorganized and reported in four major categories: (a) meaning of the illness—similarities between survivors and family members, (b) family QOL—similarities between survivors and family members, (c) meaning of the illness and family QOL—overlap in similarities between survivors and family members, and (d) meaning of the illness and family QOL—differences between survivors and family members.

Results

Sample Characteristics

The cancer survivors ranged in age from 52–75, with a mean age of 65. Family members ranged in age from 21–80, with a mean age of 55. The majority of family members were spouses (53%), followed by adult children (29%), significant others (10%), and siblings (8%). Family income ranged from less than $10,000 to more than $90,000. In this random sample, essentially equal groups of families were represented in four cancer diagnoses: breast, colon, prostate, and uterine. For this group of cancer survivors, the mean time after diagnosis was 3.4 years (range 1.5–6). The mean time after the primary treatment was completed was three years (range 1–6) (see Table 1).

Meaning of the Illness: Similarities Between Survivors and Family Members

For cancer survivors and their family members, the meaning of the illness to their family involved telling the story of their initial reactions at the time of diagnosis. The research question was designed to determine the meaning of the cancer to the family, but responses frequently revealed individuals' personal perceptions. Although some of the survivors were more than five years postdiagnosis and primary treatment, the first response to the open-ended question often revolved around the emotional reactions and intense feelings experienced by survivors or their family members when the patients were diagnosed with cancer. Themes illustrated some of the processes patients and family members used to cope

Table 1. Demographic Characteristics

Characteristic	Cancer Survivors (N = 123)	Family Members (N = 123)
Age (years)		
Range	52–75	21–80
$\bar{X}$ (SD)	65 (6.2)	55 (14.5)
Education (years)		
Range	4–20	3–24
$\bar{X}$ (SD)	12.25 (2.76)	13.21 (3.19)
Years since diagnosis		
Range	1.5–6	–
$\bar{X}$ (SD)	3.39 (1.0)	–
Years since primary treatment completed		
Range	1–6	–
$\bar{X}$ (SD)	3.01 (1.07)	–
Characteristic	**n**	**n**
Gender		
Male	45	43
Female	78	80
Ethnicity		
Caucasian	62	63
African American	61	60
Employment status		
Employed	39	58
Retired	64	47
Homemaker	20	18
Marital status		
Married	79	–
Widowed	21	–
Divorced	19	–
Single	4	–
Relationship of family member		
Spouse	–	65
Child	–	36
Significant other	–	12
Sibling	–	10
Family annual income		
$0–$9,999	13	–
$10,000–$29,999	46	–
$30,000–$59,999	34	–
$60,000–$89,999	7	–
$90,000 or more	9	–
Cancer site		
Breast	31	–
Prostate	30	–
Colon	31	–
Uterine	31	–
Type of treatment		
Surgery	108	–
Chemotherapy	28	–
Radiation	48	–
Hormone	6	–
Other	2	–

N = 246

with the cancer and how the meaning of the illness had changed over time. Four major themes were identified in this category.

Devastation or shock at time of diagnosis: The shock and fear of having cancer was a dominant theme expressed. Thoughts about mortality and the possible loss of loved ones were reported. One survivor commented, "You're in shock. I was devastated . . . you think you're going to die—no forewarning." Some family members indicated that they could not believe it was cancer until long after the diagnosis and treatment were over. One husband stated, "It was devastating to me. It took a long time to accept that it was cancer."

Taking care of the cancer: Survivors and family members shared how they dealt with and handled various cancer treatments. Decisions about the type of treatment were discussed, as was confidence in the doctors. Responses ranged from wanting the cancer out of their lives and their bodies to the cancer being a problem that needed to be taken care of and handled directly. One participant said, "We were thinking, 'what to do about it,' take action. I think that's how we look at it—take action." A subgroup of survivors indicated that they had "licked" the cancer. Several families reported relief that the cancer was treatable and had been caught early. As one man with prostate cancer indicated, "I had the radiation. I'm glad they found it and treated it before it got worse."

Not thinking or talking about it too much: A common response to the meaning of the cancer illness by both survivors and family members was not talking or thinking too much about the cancer. Participants expressed the belief that they needed to go on and handle the cancer. Efforts to minimize the cancer, not dwell on it, or not let it take control over their lives were evident. Several survivors indicated that they rarely thought about the cancer. One breast cancer survivor said that she and her daughters "try to make light of it and not talk about it too much."

Reliance on faith: Spirituality and having faith in God were important elements of the meaning of the cancer illness for many families and cancer survivors. One breast cancer survivor said, "Jesus is the best thing that ever happened to me. Even though I've been told that the big 'C' has hit me in the body, Jesus is with me . . . he has pruned me through this cancer." Family members also reinforced the importance of reliance on faith and spirituality. One wife claimed, "It's serious, but you learn to deal with it. My religion has helped me and my spirituality—I don't think [cancer] is something we can't deal with."

Family Quality of Life: Similarities Between Survivors and Family Members

Survivors and family members reported both positive and negative effects of the cancer illness on their families' QOL. Survivors ranged from one to six years after their primary treatment without recurrent disease. Many survivors and their families indicated that the cancer was now behind them and life went on. Although some were coping with long-term effects related to treatments and lingering worries about the cancer returning, most families had put cancer in a perspective of their total life experience. Four themes were found in this category.

Valuing and living life to the fullest: Surviving a cancer illness helped patients and family members reflect and appreciate the value of their lives. Several commented on how they subsequently reprioritized what was important to them. One son said, "It makes you live life to the fullest every day. Looking at my dad being forced into retirement [by the cancer] . . . this makes us step back. It makes you look at life differently. You need to prepare yourself—live life to the fullest—don't wait. It gave me a different outlook on life." Another survivor

added, "My life now is do what you want to do. Enjoy your life while you're healthy. I feel as though I've been blessed. I enjoy my life now."

No lasting negative effect on QOL: A common theme expressed by many survivors and family members was that the cancer illness had no lasting or long-term negative effect on their families' QOL. Because several survivors said that they were "okay" now, they saw no lasting negative effect on their QOL. Extended time since the diagnosis and completion of treatment appeared to contribute to this effect. One survivor commented, "I don't think the cancer has affected our quality of life—at first it was hard, but now it's okay."

Increased family closeness: A benefit of having experienced cancer was the reinforcement or improvement in family relationships and closeness. One husband said, "I look at life differently after that. I feel much closer to her. I feel the need to be closer, to be there for her—just to communicate better. It makes you look at how fragile life is." Another statement by a breast cancer survivor supports increased closeness. "It brought us a little closer together, my daughter and I . . . all my sisters, they were always supportive and concerned. This was something that we would do for each other."

Living with other stressors: Other stressors that affected family QOL were a reality for several families. Illnesses of another family member, other family problems, and limited family resources posed extra stress. Some families encountered insurance problems and a decreased income subsequent to retirement related to the cancer illness. One survivor commented, "We have a lot of sickness in our family now—we try to manage and keep the stress down." An only son who had lost his father and whose mother had been diagnosed with cancer said, "With Dad dying and not having any brothers or sisters, there's no one to help out—my mom's getting older and needs someone around."

Meaning of the Illness and Family Quality of Life: Overlap in Similarities Between Survivors and Family Members

Some themes were found that overlapped the major areas of meaning of the illness and family QOL for survivors and family members. The meaning of the illness appeared to be embedded in survivors' and family members' views of their family's QOL. This category exemplifies the interrelationship that appears to exist between meaning and QOL for survivors and family members. Themes included concerns and worries about cancer and the future and how families now were living after having experienced cancer in the family. Five major themes were identified in this category.

Going on after the cancer: A common theme expressed by many survivors and family members was living through the cancer and getting life back to normal. Comments suggested that less worry occurred over time and respondents were putting the cancer behind them. For example, "After I went through the radiation, it was okay. Life started getting back to normal. It doesn't bother me hardly at all. . . . I think about it but don't let it worry me." Several individuals commented that they saw themselves as survivors and that they were cured. "I think that I didn't dwell on it, I just had the [lumpectomy]—like taking a bad spot out of a peach—and went on. I thought I was cured." One husband added, "I felt that she had it and it's past. We survived the terror of the onset and now it's past."

Concern for cancer in the family: Survivors and family members expressed concern and worry that cancer was "in the family." Questions about the genetic or hereditary linkage of cancer within families and worry and concern for their children or themselves were expressed. One breast cancer survivor shared, "My daughters were pretty shook up about it—they worry about it being hereditary. I think, too, that my father had cancer and didn't know it." Another man offered, "We have not had good luck with cancer in our family. My mother and father both died of colon cancer." Adult children expressed similar concerns. "Just knowing that my father had this surgery has made me more aware of cancer and that it could affect other people in the family. I worry about it being hereditary." Other adult children expressed resignation. "I lost my mother and brother to cancer, so I figure we will all get it sometime."

Worrying about the cancer coming back: Survivors and family members worried about cancer recurrence. Some discussed it in terms of going for doctor appointments. "Now I don't worry about it too much, except before an appointment, then I worry at the site of my lumpectomy." Another survivor confessed, "When I get a pain, I worry whether they got all the cancer." Family members expressed similar concerns. "I worry when he goes in for tests—until we hear it's okay. I think what's down the road for us." One husband shared, "Now, I'm still scared—it's really scaring me. I had a friend who died from [cancer]. I'm still worried about it coming back. When she has problems with the blood pressure, I think it's the cancer."

Difficulty living through cancer: A small number of survivors and family members indicated that living with cancer still was difficult. Adjustment difficulties and current worries still were affecting their families' QOL. Some found it hard to believe that they, or family members, had cancer. One prostate cancer survivor revealed, "Emotionally, I felt dead [hearing I had cancer]. Now, I'm not a man anymore. Now, I go to church, do my thing, and come home. . . . Our time is on a slope, we can drop anytime." Other survivor statements included, "Sometimes it's like a jail . . . we can go up to three months away, but we have to come back. The health thing is always there," and "It's taken away a lot from you . . . sometimes it works on your mind."

Taking care of our health: Having cancer was a wake-up call for some survivors and their families. One prostate cancer survivor said, "It made my sons more aware of getting tests early on for their own health." Early intervention and treatment meant cancer did not have to be a death sentence. "It means not to let it go too long. It opened my children's eyes about me and taking care." Another survivor added, "Prevention and yearly detection is the important thing. You really have to take charge of your health."

Meaning of the Illness and Family Quality of Life: Differences Between Survivors and Family Members

Cancer survivors noted the importance of receiving support from others, whereas family members mentioned support in the context of showing concern and giving support to the patients. Family members usually kept their feelings to themselves and maintained a positive attitude. Survivors, however, openly expressed concern that their families were distressed and worried about the cancer. A major theme for family

members was that of coming together as a family, whereas patients were more concerned about long-term effects from various cancer treatments.

Receiving support from family, friends, and healthcare professionals: The importance of receiving support from people in their lives was a major theme for survivors, both in meaning of the illness and the effect on their families' QOL. One survivor of uterine cancer commented, "Through the whole cancer experience, there were many people to give me support and encouragement . . . our sons were very aware, they were young at the time. They were very sympathetic, they didn't take a negative approach—'oh Mama, you're going to be okay, you're not going to die.'" Several commented that they couldn't have gone through the treatments without the support of their families. Survivors also noted the support received from healthcare professionals, particularly physicians, while they were dealing with the cancer illness.

Dealing with long-term physical concerns: Both in meaning of the illness and QOL, facing long-term physical concerns secondary to cancer treatments was evident for survivors. These concerns included compromised sexuality, fatigue, bowel and bladder problems, and lymphedema. One prostate cancer survivor commented, "It's taken away a lot from you—you really don't have the action, the feeling. You feel like a cripple. Sometimes it works on your mind." A breast cancer survivor commented on the effects of lymphedema. "It was upsetting. It was a shock to me because I didn't realize it would be such a big change. I've had a few people who have not been kind—making comments about my arm."

Worry and distress for family: Survivors were sensitive to the worry and distress that their family members were experiencing. They discussed how their spouses and children were "shook up" about the cancer, thinking "this was the end." Patients worried how their families would handle the cancer and other treatments. One survivor commented, "I was worried about my wife . . . it was tough at first for her." Several survivors commented that family members were more upset than they were. One survivor offered, "It worried my family . . . you would worry if you found out it was happening to someone close to you."

Showing concern and keeping feelings to self: Family members discussed their role in the cancer experience as giving support to their loved ones and showing concern. An element of this concern was keeping their own feelings to themselves. One family member said, "I looked at her moods and tried to give her what she needed. I don't know how I dealt with my own feelings. I guess I keep them in." Another said, "I was mostly concerned about her and how she would deal with it. But you just have to learn to live with it. With our family, we were worried about her."

Other family members expressed their concern about the survivors dealing with long-term physical effects from treatment and their attempts to reassure them. One wife of a prostate cancer survivor commented, "The injections have affected my husband's [sexual] performance. That's very hard for him. I tell him that it's much more than that—companionship is very important."

Coming together as a family: Some family members emphasized that the diagnosis of cancer and their active participation in the treatment brought their families closer together. One son noted, "I think it was very positive for our family. The way my siblings and Dad took care of the dressings—we really had to hang together." As one daughter said, "I think it brought us closer together as a family. Going through this with my mother has been an education, learning about cancer and treatments."

Discussion

Overall, the majority of survivors and family members indicated that positive dimensions to cancer survivorship existed in the meaning of the illness and family QOL. Survivors and family members discussed how they went on after the cancer illness and returned to a more normal family life. Family attempts to regain normalcy and balance have been seen during initial diagnosis (Hilton, 1996) and recurrence (Lewis & Deal, 1995). The current study suggests that such family patterns may extend into a survivorship period one to six years after treatment has ended. The emphasis on what was of real value in life and the importance of family bonds and relationships also reiterated positive dimensions of survivorship. Previous researchers have uncovered the transformational quality of living through and surviving a cancer illness for individual patients with cancer (Taylor, 2000; Utley, 1999). In this study, many family members also exhibited "transformational" characteristics of surviving along with the patients and reevaluating their lives. Additional emphasis on taking care of health and early prevention and treatment were other positive aspects of survivorship for cancer survivors and family members.

In this study, meaning showed both individual- and family-level dimensions. Although the two open-ended questions asked about individuals' meaning of the illness to their families and its effect on their families' QOL, a majority of the survivors and family members told their individual stories about their cancer experience and what seeking meaning was to them. However, survivors and family members also viewed the meaning of the illness within the context of their family life. Families described "going on" after the cancer, an emphasis on family relationships and closeness, and the meaning they attached to having cancer in the family. The meaning of the cancer also appeared to change over time and overlapped with dimensions of QOL. The literature has cited the importance of addressing the linkage between meaning and QOL (King et al., 1997; Zebrack, 2000a). Some researchers have begun to explore meaning and its relationship with QOL (Dow et al., 1999; Zebrack, 2000b). In the current study, several themes emerged for survivors and family members that intersected with meaning and QOL. A possible explanation is that the cognitive appraisals and meaning of the cancer by the survivors and family members were interrelated with and may have contributed to their family QOL.

Changing perspectives on meaning has relevance to stress and coping theory. Folkman (1997) and Park and Folkman (1997) have suggested revisions in the traditional coping processes to emphasize the search for positive meaning. According to Folkman, four processes are involved: positive reappraisal or reframing of the situation, problem-focused coping, spiritual beliefs and practices, and creating positive meanings in ordinary events. In the current study, evidence exists of these processes and the search for positive meaning. Survivors and family members attempted to reframe the cancer as something that they were glad was diagnosed early, treated effectively, and now behind them. They also described their

reliance on spiritual faith and their increased appreciation of everyday life processes, which also was reported by Folkman.

Another dimension of meaning of the cancer illness was evident in how families communicated. Some family members commented that their families were drawn closer together and had improved communication following the cancer diagnosis. However, some family members tried not to think or talk about cancer too much. The idea of families keeping some control over the cancer by not discussing it too much may be indicative of a family's coping style. Previous research with families facing a new diagnosis of cancer (Hilton, 1996) and families with recurrence (Lewis & Deal, 1995) identified similar patterns of minimizing and not talking too much about the cancer.

Although positive dimensions of survivorship were noted by this sample, longer-term stressful effects of having cancer also were reported. Survivors and family members expressed ongoing worries about the cancer recurring. Although patients were doing well at the time of the interviews, the possibility that the cancer might return was a chronic stressor for many families. Also, a small number of survivors and family members still were struggling with having cancer in their families and appeared to have difficulty coping with side effects from treatment. Another long-term effect was the ongoing concern about cancer in the family. Some families expressed the concern that cancer now was "in their families" and wondered what the implications would be for their children and siblings and themselves. With recent international attention on the Human Genome Project, the focus on genetic testing and the need for family-focused intervention and care will grow (Feetham, 1999; Rolland, 1999; Williams & Schutte, 1997).

This sample of cancer survivors and family members had more similarities than differences in their perceptions of the meaning of the cancer illness and its effect on their family QOL. Survivors and family members articulated similar positive dimensions of meaning and QOL during the cancer experience, as well as similar ongoing concerns and stressors. However, differences existed between survivors and family members, primarily in perceived social support. Survivors perceived the strong support from family members and other healthcare professionals. Although survivors were sensitive to the distress that their families experienced, they focused primarily on the support they received. Family members, on the other hand, tended to conceal their feelings and viewed their role as providing rather than receiving support. Family members tried to remain optimistic and often kept feelings to themselves. Similar to other studies (Davis-Ali et al., 1993; Northouse et al., 2000), family members perceived receiving less support than patients during the survivorship phase. The current study further reinforces that families may need ongoing support throughout cancer survivorship.

Clinical Implications

Several clinical implications for nurses are suggested from these study results. First, the meaning of the cancer illness has importance at both individual and family levels. Nurses must determine the meaning for individuals with cancer and their family members. Offering opportunities for survivors and family members to tell their stories about the cancer may enhance the search for positive meanings. This could assist patients and family members in coping with the cancer and improve family QOL. Finding positive meaning can help reframe the cancer experience, act as a guide for specific problem-solving in day-to-day activities, and tap into spiritual beliefs and practices that can be helpful to enhance family QOL.

Second, nurses should directly address potential stressors that are present during cancer survivorship and affect family QOL. Fear of recurrence appears to be a chronic stressor for both individuals and families. Encouraging survivors and family members to openly express their fears of recurrence can assist them in reframing and putting those fears into a manageable perspective. Exploring families' genetic histories and identifying risk factors for children and siblings may provide opportunities for prevention or early detection of cancer. Emphasis should be placed on symptom management in cancer survivorship after treatment has ended because side effects may be ongoing.

Third, findings suggest that enhancing families' present strengths and communication styles could limit negative meaning and promote higher QOL. Helping families identify their strengths will assist them in coping with the long survivorship period often associated with cancer. Identifying and intervening to meet the support needs of patients with cancer and family members may further enhance family ability to manage a cancer illness. In this study, a variety of family communication styles were seen, ranging from open communication to not talking too much about the cancer. Assessing a family's communication style is critical in helping it achieve a level of disclosure that is comfortable for the family while still addressing the needs of both the survivor and family members.

Fourth, nurses should identify and intervene with families who are having difficulty living through the cancer experience. Although the vast majority of survivors and family members in this study indicated that no lasting negative effect on their family QOL occurred, a small number indicated that their family QOL had declined since the cancer illness. Early identification of patients and families who are struggling with the stress of having cancer is vital to helping them adjust to this disease.

Study Limitations and Recommendations for Research

Although these qualitative results provided descriptions of one sample of cancer survivors and their family members, the use of a onetime interview using two open-ended questions presents methodologic limitations. An in-depth, qualitative study over time using phenomenologic methods would enhance future research of cancer survivors and families during the survivorship period and contribute to a better understanding of their needs. Results of this study pertain only to survivors who were no longer undergoing treatment or had not experienced a recurrence. Other survivors, who have had a recurrence or currently are undergoing treatment, may present different findings.

Further research is needed to examine the meaning of cancer within the family and the family's particular communication styles that enhance or hinder its cancer survivorship experience. The chronic stress of worry about cancer recurrence needs ongoing attention for both survivors and family members. Although this study's results contributed to the family

survivorship model, the need exists to further address meaning of the illness from an individual and a family context and how the search for meaning is related to effective coping strategies for families. Research also is indicated to explore the meanings of the cancer experience for both survivors and family members and their relationship to QOL throughout survivorship.

Summary

This cross-sectional, qualitative study provided information about similarities and differences between cancer survivors and family members in the meaning of the cancer illness and its effect on family QOL during a survivorship period one to six years after treatment had ended. Many positive aspects of cancer survivorship were evident both in the meaning of the illness and family QOL. Although positive aspects of the cancer experience were noted, long-term effects and concerns related to cancer survivorship also were seen. Overall, more similarities than differences were detected between survivors and their family members. The differences highlight the importance of addressing individual concerns that are present while also incorporating a family perspective during cancer survivorship. Both individual- and family-level interventions are critical to promote QOL and well-being for both cancer survivors and their family members.

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For more information . . .

- Cancer Survivors Online
  www.cancersurvivors.org
- Cancer Survivors Network
  www.acscsn.org
- National Coalition for Cancer Survivorship
  www.canceradvocacy.org

These Web sites are provided for information only. The hosts are responsible for their own content and availability. Links can be found using ONS Online at www.ons.org.