ARTICLES

This material is protected by U.S. copyright law. Unauthorized reproduction is prohibited. To purchase reprints or request permission to reproduce, e-mail **reprints@ons.org**.

Nurse Experiences as Cancer Survivors: Part I—Personal

Rosanna F. DeMarco, PhD, APRN, BC, ACRN, Carol Picard, PhD, RN, CS, and Joan Agretelis, PhD, RN, AOCN®

Purpose/Objectives: To uncover dimensions of nurses' personal experiences of cancer survivorship.

Design: Interpretive, phenomenologic.

Setting: Metropolitan area in the northeastern United States.

Sample: 25 RNs diagnosed with cancer. Average age was 50 years, and 20 participants were less than five years from initial diagnosis.

Methods: Interviews. Analysis using methodology of Newman (1994, 1999) and Van Manen (1990).

Main Research Variables: Nurses' personal experiences of cancer survivorship.

Findings: Themes of the nurses' personal experiences of survivorship included the shock of becoming a patient and multifaceted dimensions of the treatment experience, including time, coordinating their own care, the struggle to maintain normalcy, uncertainty, nonclinical self-care strategies, and encounters with caring and uncaring providers. Participants identified the need for supportive relationships both in personal and professional arenas throughout the survivorship process. The cancer experience became an opportunity for change in priorities.

Conclusions: Although nurse cancer survivors experience similar personal vulnerabilities to those of non-nurses, their vulnerabilities often are affected by their knowledge of the healthcare process and content of care with which they are most familiar. They also are affected by what they know is at stake. This particular insider vulnerability is not cited often in research literature and, therefore, is not recognized as a particular type of need that should be addressed in cancer survivorship.

Implications for Nursing: Nurse patients need providers to be sensitive to their information and support needs, which may vary because of their professional experiences and personal resources. Findings suggest that nurse patients may need supportive approaches that target their unique vulnerabilities.

ancer survivorship is a process. More than 8.4 million Americans are living with a cancer diagnosis, and 65% of those diagnosed with any form or stage of cancer have survived for more than five years (American Cancer Society, 2004). Because nurses are aging as a cohort, with an average age of 45.4 years (Buerhaus, Staiger, & Auerbach, 2000), these professionals are in a higher risk group for the diagnosis of cancer. The National Coalition for Cancer Survivorship (2002) defines survivors as people liv-

Key Points...

- Personal experiences of nurses can affect their cancer survivorship.
- ➤ Healthcare providers should not assume that nurse cancer survivors have fewer needs than other patients.
- Nurse cancer survivors have unique needs that require exploration.

ing through and beyond a cancer diagnosis. When nurses are diagnosed with cancer, the process of their survivorship is one of living in two worlds, that of patient and provider. In the age of evidence-based practice, what constitutes evidence for excellent healthcare practice should include the voice of the patient. Research that uncovers missing evidence of the voice of nurses with cancer creates an opportunity to give a voice to nurses who live with this experience. The healthcare community also is responsible for investigating and responding to the needs of special populations of cancer survivors such as healthcare professionals. According to Kayser, Sormanti, and Strainchamps (1999), women in particular experience more positive psychosocial adaptation to cancer when they share their experiences through mutual relationships. Because nurse survivors hold positions as "insiders" as

Rosanna F. DeMarco, PhD, APRN, BC, ACRN, is an assistant professor in the Connell School of Nursing at Boston College in Chestnut Hill, MA; Carol Picard, PhD, RN, CS, is a professor in the Department of Nursing at the University of Massachusetts Lowell; and Joan Agretelis, PhD, RN, AOCN®, is a regional medical manager for New England for Sanofi-Synthelabo Oncology, based in New York, NY. This research was supported, in part, by research grants from the Kenneth B. Schwartz Center and a National Institutes of Health Clinical Research Center Grant at Massachusetts General Hospital (M01-RR-01066). (Submitted November 2002. Accepted for publication April 20, 2003.)

Digital Object Identifier: 10.1188/04.ONF.523-530

healthcare professionals, the potential exists for a deeper understanding of the process of care delivery and patient needs by engaging nurses in this inquiry. The aim of this study was to uncover the dimensions of nurses' experiences related to their professional roles and their experiences of receiving care as cancer survivors.

Literature Review

According to Farmer and Smith (2002), attributes and themes of cancer survivorship have been addressed in the research literature as (a) a phenomenon filled with complexities such as physical and psychosocial development (Auchineloss, 1995; Breaden, 1997; Carter, 1989; Ferrell & Dow, 1996; Leigh, Williams, & Stovall, 1998; Pelusi, 1997), (b) an individual journey (Breaden; Carter, 1993; Dow, 1990; Ferrell & Dow; Krause, 1991; Pelusi; Utley, 1999), (c) a process trajectory that evolves over time (Breaden; Carter, 1993; Dow, 1990, 1991; Dow, Ferrell, Haberman, & Eaton, 1999; Gambosi & Ulreich, 1990; Leigh, 1994, 1999; Leigh, Boyle, Loescher, & Hoffman, 1993; Leigh et al., 1998), (d) a unique and deeply personal experience (Auchincloss; Dirksen, 1995; Ferszt & Waldman, 1997; Harrell, 1972; Loescher, Clark, Atwood, Leigh, & Lamb, 1990), (e) a relational experience (Lee, 1997; Ott, 1997), and (f) a specific dynamic concept that defines and describes a state of being that changes over time (Utley).

Descriptive and research literature in general nursing, oncology nursing, and general oncology publications give evidence over a decade to descriptions and new knowledge regarding the survivorship experience. In many cases, survivorship studies address group or individual experiences from a variety of demographic comparisons, including age, diagnosis, prognosis, and trajectory of oncology care. However, much of the literature limits the meaningfulness, cultural relevance, and implications of the findings by not considering the effects of a particular occupational orientation on survivorship (i.e., healthcare providers, specifically nurses). Few reports have been made of nurses' experiences of cancer survivorship. Autobiographical essays have identified the professional nursing role as somewhat problematic, with examples of frustration with the healthcare team's failure to listen or provide support and information ("Is cancer different when you're a nurse?," 1982; Simon, 1978). Hamilton (1999) identified self-evaluation as part of her own cancer survivorship, noting a renewed emphasis on what was essential and important in her life. Other first-person nurse essays and reports identify similar themes ("Is cancer different when you're a nurse?"; Nally, 1999; Scannell, 1985). These nurse cancer survivors identified the self- and professional roleenhancing perspectives they gained from being patients.

No research studies on nurses' experiences of cancer survivorship were found in the literature. Also, no research reports were found on other healthcare professional groups' experiences of cancer survivorship. This study was designed to answer two questions related to RN participants: What is being a cancer survivor like, and what has this experience been like for you personally and professionally?

Methods

Design

The study is based on phenomenologic concepts from caring theory of Watson (1990) and the theory of health as ex-

panding consciousness of Newman (1994). The authors believe that caring is an essential component not only of health-care practice but also in the conduct of cooperative inquiry. Rather than a dispassionate stance for the researchers, this is a form of engagement and full presence to listen to the stories of participants. Newman challenged the somewhat artificial distinction between research and practice when engaging in narrative inquiry, because the telling of a story can provide participants with insight and an enhanced sense of connection in this partnership of exploratory research.

A phenomenologic design was selected to meet the aim of the study. Researchers employed a method of cooperative inquiry developed by Newman (1999). It is a form of participative research, in which the outcomes of research can take the form of self-awareness and insight for participants and knowledge for the professional community.

This article reports the nature of the personal experience of cancer survivorship for nurses. Findings in regard to participants' professional experiences are reported in part II (see page 537). Participants shared their stories of living through diagnosis, treatment, and survivorship. Researchers met with participants for two in-depth interviews.

Sample

RNs who had been diagnosed with and treated for cancer were recruited in the northeastern United States through print and e-mail postings in major teaching hospitals and postings in selected professional publications. Because qualitative research sampling is a function of both the number of interviews and the number of people involved, Morse (2000) suggested a small sample size as represented in this study. Previous studies using this method (Endo et al., 2000; Jonsdottir, 1998; Lamendola & Newman, 1994; Newman & Moch, 1991) confirmed the adequacy of the sample size for this study design. Of the 25 RNs participating in the study, 23 were women. The age range of the total sample was 33-66 years, with most of the sample (n = 17) older than 46. The time from diagnosis ranged from six months to 16 years, but most (n = 20) were within five years of diagnosis. Cancer sites and types varied: breast (n = 16), chronic myelogenous leukemia (n = 1), colon (n = 1), esophageal (n = 1), Hodgkin's lymphoma (n = 1), lung (n = 1), melanoma (n = 1), mucoepidermoid parotid (n = 1), ovarian (n = 1), and spindle cell soft tissue sarcoma (n = 1). The nurses worked in a variety of healthcare settings, including advanced practice, emergency care, intensive care, medical/surgical units, management, mental health units, community health, school health, education, pediatrics, and oncology.

Data Collection and Analysis

Each participant was interviewed twice, in the researchers' offices or at the homes of participants, depending on participant preference. Each participant saw the same researcher for both interviews. All interviews were recorded on audiotape and transcribed. In the first interview, participants were invited to answer the research questions. Participants were invited to share writings or other modes of expression with the researchers as well. During the second interview, the researchers shared their understanding both in text using the participants' own words and in a piece of reflective artwork that the researchers generated. (A report on the reflective artwork [Picard, Agretelis, & DeMarco, 2004] will be the subject of a future publication.) In the

second interview, participants had the opportunity to edit, clarify, or expand on their stories. Subsequent analysis examined the common themes across participants' stories, using Van Manen's (1990) approach of a detailed line-byline examination of text, identifying sentences that captured dimensions of the experience. Elements of meaning were identified and considered in relation to the whole, with themes generated across participants' stories.

Rigor and Trustworthiness

Rigor was addressed through adequacy of data collected from multiple data sources (i.e., two interviews, creative materials shared by participants, and researcher field notes and journals); dialogue with participants for validation used to confirm that the interpretation of meaning was in keeping with the participants' reality; and regular meetings of the research team using a reflexive process of dialogue as they examined all data sources. Representativeness of the data in describing process across participants was addressed by creating a data grid to analyze themes across participants.

Findings

This article reports on the results of analysis across participants on the personal experiences of cancer survivorship. Professional experiences are reported in part II. Themes of survivorship included the shock of becoming a patient and the multifaceted dimensions of the treatment experience, including time, coordinating their own care, the struggle to maintain normalcy, uncertainty, nonclinical self-care strategies, and encounters with caring and uncaring providers. Participants identified the need for supportive relationships both in personal and professional arenas during and after the treatment experience. The assets and liabilities of being both nurse and patient were identified. Survivorship was identified as an opportunity to reorder priorities and achieve a sense of balance.

Shock of Becoming a Patient

Being nurses delineated participants' role in the healthcare environment. Crossing into the world of the patient, most participants were unprepared for the feelings of vulnerability associated with a cancer diagnosis. Throughout the process of diagnosis, treatment, and survivorship, the role and position as patients enhanced the nurses' awareness of just how vulnerable they can be. One nurse described how working in acute care colored her emotional response to the diagnosis.

Sometimes I think it's more frightening as a healthcare worker. . . . The reason I say that is because we see the worst in the hospital end of things. So we see all the bad outcomes. And health care . . . those colleagues that I'm around, there's sort of this bad aura around cancer. And so . . . sometimes I think it adds to the fear as well as my own knowledge.

Although appreciating the patient's experience is a part of nursing education and also a factor in patient quality review and management approaches in health care, stepping into the patient's world made the theoretical come to life for participants.

And I guess I was like, oh, my God, all those things that I read in those books, when I was a nursing student a million years ago, that you kind of read it, you're like, okay, that makes sense, but the . . . loss of self, as you know yourself, when you become a patient, you read that in terms of your helping your patients get through that. Or, for me, most of my professional career has been helping parents get through their child's illness, and I didn't. . . . The emotional impact of that became so clear. . . . I had this feeling of, I guess, loss of control.

Being Nurse and Patient: Asset or Liability?

Being a nurse had its advantages and disadvantages. One advantage for many of the participants (n = 14) was being able to access resources and expertise within the healthcare system that they knew well to expedite their care. Some nurses were able to assemble their treatment teams themselves or with the help of friends who worked in their care facilities.

A friend of mine is the transplant coordinator down there. She picked all my team. So I did have, she picked everyone she would want to go to, and the nurses down there are really wonderful.

Other participants found that providers made assumptions about their level of knowledge about their treatments by virtue of being nurses. For almost all, oncology was not their field.

I wasn't prepared at all for—for anything. I think the assumption was, I was a nurse, I must know what was going to happen. And I found that very difficult. When I was getting ready to be discharged in the morning, when I asked about having a visiting nurse when I went home, and he said, "Well, you're a nurse, you should be able to take it. You should be able to take care of it yourself." But you go home with a drain. You go home with a Jackson-Pratt, you know. My first—my biggest fear was that the first time I changed the dressing it was going to fall out.

Although nurses often wanted to access insider information, they wanted to choose what additional information they received. One nurse described the unhelpful experience of being presented with scans of his inoperable tumor.

So I don't want to see what you can't take out of me. If you can take it out, I'm right there. . . . I didn't know why she was bringing me back there and suddenly she was showing me, and I was like, "I'm going to be sick."

Time

Nurses described the importance of time and how it was managed among suspicion of cancer, the diagnostic process, and treatment. They felt an urgent need for the expedient resolution of the diagnostic process.

I actually had started not at my own institution, another institution, and I found that it wasn't as quick and as timely as I wanted, and that's why I came here, and I was admitted for my first cycle of therapy and everything. . . . Things happened much quicker for myself, and for me that was good. And I think for most patients, time is of the essence. Because anxiety can really play a big trick on you.

Another nurse waited to hear a second opinion about her questionable pathology report over the holidays.

People kept on telling me to be patient, and so finally on January 2nd, when I hadn't heard, I picked up the phone and called the surgeon who had done the biopsy. And I said, "You know, it's been almost two months, and I need to find out about what's going on." And he said, "Well, I'll call you back." And the next day, he called. Now, I know that that report was probably sitting on his desk, you know. It just got probably lost in his holiday stuff, too; but it's amazing to me—that was the first inkling of the medical system—of working with the medical system.

Coordinating Their Own Care

Most nurses spoke about the need to be coordinators of their own care, conveying information from one provider to the other. They frequently commented on how much more difficult this must be for lay people. Although some liked being in control of their care, most wished providers had been keeping track and speaking to each other.

I also had access to the hospital computers, so I could look up my own lab work, which like, okay, that's why I feel so bad, you know. You know, you do have a little inside information, you can say, okay, that's past, now I need my chest x-ray this month, I need *this* this month, and I need *this* this month, you know, and she'd say, oh, okay. It was almost, I was kinda directing a lot of it in some respects . . . which I guess kind of gave me a feeling of control 'cause you do lose a lot of control when you go in the hospital, so I think, you know, that helped.

The appreciation of their insider role was not lost on participants, who reflected on such a task for members of the public.

I felt I had to coordinate my care, when my bloods needed to be drawn, when I had to have my x-rays, when I had CT [computed tomography] scans needing to be done, it was like, okay, I guess I have to take charge of this 'cause nobody's keeping track.

Taking control was a coping strategy for many participants at the time of treatment, but, in retrospect, it was not always thought to be the best strategy.

I was so nauseous, but for whatever reason I didn't dare go and tell anybody because I felt as though I needed to take care of the situation myself. You know, here I am a nurse, and an oncology nurse at that, and I needed to take care of the situation myself and I, you know, I just remember having all those feelings about that and saying, you know, how much I kind of wished I took some of that time just to be the patient and maybe took a little time off from work or, you know, something to transition me from the time of being a patient to the time of just . . . I don't think I ever took that time to be the patient.

The Work to Maintain Normalcy

Nurse participants worked to balance treatment, family, and professional commitments. Nurses' efforts to maintain their work schedules as a means of maintaining normalcy are described in part II. Although coworker and family support contributed to their choice to continue work and active involvement in family life, generally they made a personal decision to regulate their energy and maintain their multiple roles as they did before their cancer diagnosis. A particular challenge was the ambiguity in their relationships with family members. Instead of being the caregivers, they now needed to receive care. This was not an easy role to assume, and many who were parents expressed great concern for their children, as well as for spouses and their own parents. Telling family members of their diagnosis was very difficult, and treatment presented further hardships. One nurse, a mother of a six-year-old, said,

He looked up at me and said, "Mommy, who's gonna take care of me when you die?," and all of a sudden I realized he knows a lot more than he's let on, and that threw me the most rather than anything else. [Describing a post-treatment day] He was there with me when I was throwing up and everything, and he goes down on the ground and covers his ears and says to me, "Mommy, please don't do this anymore," and it was the most difficult [crying].

Participants made great efforts to keep things as normal as possible for their families. Fatigue, nausea, pain, and discomfort during treatment often prevented this from happening.

I would try to say, "Why don't we go out for dinner somewhere," and I'd be feeling sick all the way, and we'd turn around in the car and go back home. Because I just wanted to be normal.

Experiences of Caring and Uncaring Behaviors of Providers and Colleagues

Participants had mixed experiences of caring and uncaring encounters with providers and colleagues. Caring was experienced as both compassion and competence. Compassion was experienced as being known as a person to the provider. Simple gestures such as e-mail contact, inquiring as to their feelings, or visiting them when hospitalized were highly valued. When the element of compassion was present, it could make all the difference in getting someone through treatment. One nurse had to have a therapeutic abortion of her first pregnancy upon diagnosis.

(My oncologist is) just so wonderful. And then the oncology fellow, he and I are similar age, and his wife just had two babies, or within two years had two babies. So we're in the same life phase, and I think he could really relate to me. And he would always go through the medical, "What are you having for symptoms, how are you managing it," and, you know, "Are you doing okay, are you getting through this?" And he'd always say to me, like, scan to scan, you know, he knows I would like to, at some point, even if I could, bear one child, and he doesn't let me lose that hope. He talks about that every visit. It's not out of the question, maybe we'll get there.

In most instances, coworkers provided elements of support, with varying modes of expression. Some coworkers provided postoperative care or home care, took nurses to appointments, or simply kept in touch through cards, letters, or e-mail. My work group was probably the biggest surprise because I knew that they would be supportive, but I had no idea to what extent. But they sent me all kinds of presents, and they would call all the time, and when I was in the hospital, they'd come and see me, and I would walk on the unit, and they would all run up to me, and I just felt so loved and so protected.

Participants identified professionals as uncaring when they lacked compassion and did not treat them as individuals. Such encounters created distress. Some nurses changed providers to ensure that their care was given competently and compassionately. They valued the establishment of a relationship as the context for the provision of care. During short hospital stays for surgery or other treatments, this element of relationship often was missing, but the need for compassion still existed. Lack of sensitivity to a patient's experience during painful procedures created suffering and a sense of isolation.

I had a resident come in and take my, I had two Jackson-Pratt [JP] drains, he came in and did not introduce himself to me. He said, "I'm going to take out your JP," and he took them out, and I have never felt such pain. But I was by myself, and I think that was the only time I was alone because I didn't have a family member stay overnight with me, and I was alone and I just started to cry and I hadn't until that point. And I just felt like he was so cold and if he had just taken two more minutes to kind of say, "Is this an okay time" or "I have to do this, it's going to be uncomfortable," anything. But he just kind of came in and went to work, which was really a bad way to do it.

The participants valued being fully informed about all aspects of their care. Although information may have been correct and accurate, it may not have been caring or helpful to share with the people undergoing treatment.

One person said to me, a nursing person, years of experience, she said, "How are you doing?" I said, "You know, I have a really good attitude," I said, "You know, in my family, and I know that, uh, you know, my mother survived, and my uncle, and . . . you know, I feel like my surgeon just really feels like he went way beyond where we had to and that it's just, you know, we really got it." She said to me, "Well, do you know the survival rate? I said, "Well, what are you trying to say? I shouldn't be optimistic?" And she said, "Well, you know," she said, "Yeah, you just, uh, it's good that you're feeling so good about it, but," she said, "you have to be realistic, too." And I'm thinking to myself, "Is that the right thing to say to somebody?"

Continuing Need for Support

The majority of nurses described the need for continued support throughout treatment and beyond. With few exceptions, they identified a number of supportive people in their personal lives who sustained them. However, a lack of support from others sometimes triggered feelings of isolation.

See, I'm cognizant of all of this, but still I have to turn around and feel it. And I realize a lot of people don't want to go here with me at all.... Sometimes I feel like I should call a friend. They really deflected a lot of things that I was feeling, maybe because they were

afraid. . . . Sometimes I just need to explore what happened. . . . I don't want an answer; I don't want them to fix this for me.

Although some nurses found joining support groups unnecessary because of their high level of personal and professional support, a small number did participate in support groups. Many nurses felt uncomfortable thinking about joining a formal support group despite their need for such support. They struggled with taking on the personal role of a cancer survivor with that of their professional role as nurses. They were uncomfortable sharing feelings of frustration with the healthcare system during their care because it was part of a system to which they belonged. They also found themselves taking care of others in the group. This caused them to further identify as nurses and became a barrier to getting their own support needs met. Some participants raised concerns about support groups not matching their survivorship perspectives. Some thought that their cancer diagnosis and treatment were different from other group members and that identifying with others in the group was difficult (e.g., having lung cancer when most members in a group were surviving breast cancer treatment).

Uncertainty

Uncertainty took the shape of fear of cancer recurrence and the worry of interpreting bodily symptoms as something more serious than they would have otherwise. Pain in particular created a sense of unease and worry. Uncertainty drained participants' energy and created anxiety. One nurse discussed the energy required for each medical follow-up appointment.

Someone likened cancer to a pink elephant, and the pink elephant initially is right there in front of your face, you know . . . and then as you get better, the pink elephant maybe goes to another room. And then as you get much better, the pink elephant goes down the street, but it's always there and you always know it's there. And, I think that, as you approach appointments, the pink elephant [from] down the street, you know, comes in the living room again.

Others expended large amounts of energy to keep hopeful and felt the added burden to do the same for friends and family so that loved ones would not worry. Whether recurrences happened or participants felt as if they were looming in the future, the awareness of needing to integrate the unknown into life was a part of the survivorship process.

I've always wanted that feeling that I don't have to worry about it any more or to think about cancer, and it just hit me all of a sudden that I'm always going to have to think about it.

Nonclinical Resources: Attending to the Whole Self

Most nurses used nonclinical strategies and resources. Many discussed the importance of personal commitment to prayer and participation in services in their respective faith traditions. They appreciated prayers received from others. Other complementary or integrative therapy strategies included yoga, therapeutic touch, meditation, writing and reading poetry, journaling, and acupuncture. The benefit of nonclinical interventions was surprising to some of the nurses, although they had suggested these ways of coping to many patients in the past.

If anybody had ever told me that two hours of meditation and art and writing was going to be something that I was going to find helpful, I would have told them, "You're crazy." And it sort of calms you just by helping you put things into perspective.

Survivorship as an Opportunity

Many of the participants saw cancer survivorship as a "wake-up call," an opportunity for change and reflection. Reflecting on what is most important in life, making choices to use time wisely, and balancing personal and professional commitments had significant benefits for their personal wellness.

I think everybody experienced something new, and it's . . . I mean, it's a strange thing to say, but I'm a little bit thankful this happened. A little bit. Not enormously. But a little bit thankful that this happened because it did make the transition that was necessary.

The ability to experience illness as an opportunity was influenced by the level of support in the person's life. Without support, the process could be overwhelming and alienating. One participant whose husband also had cancer and died shortly after her treatment felt particularly alone struggling with her survivorship process. She tried to put the experience behind her and does not talk of the complexities of her own illness or the death of her husband to others: "I mean, I'm basically at the point where I don't even like to tell people because it's kinda too much."

Participants spoke about their sense of renewed spirituality and faith as a result of the experience. The nurses expressed their faith in a variety of ways, through prayer, worship, and relational connections to families and faith communities. Nurses talked about having strong spiritual backgrounds and thanking God each day for things that were taken for granted.

This brought me to another level, and I do something on a daily basis that I didn't do before. . . . I have a guide book that I read every day and use like a thought, and I make a special effort, you know, effort to connect on a spiritual level, and this is comforting, very comforting.

Discussion

The personal vulnerability inherent in coping with the shock of a life-threatening illness requires much energy and support. Perhaps this vulnerability is different and more intense for nurses than non-nurses. This intensity is related to high levels of knowledge and experience in the process and content of care that nurses easily can recognize, as well as a unique understanding of what is at stake. Nurses know what is missing from care and may know where to resolve what is missing through a specific healthcare facility or the system in general. Some nurses can seek out a caring, interactive, or sensitive caregiver by reputation or direct experience. This is something that would be difficult for a non-nurse to do. A non-nurse would know only what they experience as a consumer at face value without a context, ideals, or a "memory" of direct caregiving.

Constant mental comparisons get "played out" for nurses in the trajectory of their own care based on needs to be in control that are reinforced in the workplace. The need for control over care expectations with which they are familiar is perhaps more frightening for them than for other cancer survivors. Ferrell's (1996) findings of the need for control as an element contributing to a survivor's quality of life was reflected in these findings. For example, although nursing is a science situated in the context of other sciences, the view of a tumor on a scan as a miracle of science betrays the spirit of the professional who uses science regularly to control problems and issues in practice. Experiencing uncaring environments and perhaps healthcare providers is equally betraying.

Aspects of care that are critical in nursing practice, such as timing and coordination, create unique dilemmas for nurse cancer survivors. Because of insider knowledge, nurses are more aware of the normal time necessary for biopsy results to be available. They know that not hearing any news may mean the news is not good, lost, or part of a long list of things waiting to be completed in a healthcare provider's office. Nurses also know what is needed in their care. An intense vigilance can exist to match care approaches they know with what is offered or received. This vigilance can be a burden, and the experience may be disappointing. What also may be a burden is the reality that nurses expect and take pride in the extent of their healthcare and science knowledge. Every nurse does not specialize in oncology care. Tension may occur when a nurse is considered knowledgeable when really he or she may be in the same position as a non-nurse in dealing with confusing and new treatments.

Another unique burden is the feeling that nurses need to personally orchestrate a provider plan that requires making all of the connections with personal and professional relationships to craft the best cancer care team. Although the insider experience allows nurses to use their professional autonomy more freely to accomplish this task, it also requires extra energy and work while in the midst of surgery and other treatments.

The data in this study give evidence that, like other cancer survivors, nurses describe their experiences as complex, affecting their personal and relational lives. The findings support the conceptualization of health within illness (i.e., within suffering and pain, personal and spiritual resolution occur to find balance in a new way [Moch, 1989]). Cancer became a stimulus for personal reflection, changes in priorities, and connections with the world. Dow et al. (1999) and Fredette (1995) reported similar findings in the identification of meaning, balance, and wholeness as factors in the quality of life of patients with cancer. Ferrell and Dow's (1996) research concurred that a transition occurs to a different life by virtue of the cancer experience. These findings reflect the life-changing potential of a serious illness such as cancer. The brush with mortality for the nurse participants created a new appreciation of the limited nature of time and the need to reflect on choices of how to use time and resources wisely. Pelusi (1997) suggested using Reed's theory of self-transcendence to describe the process, and Halldorsdottir and Hamrin (1996) used the term "redefinition of self." All speak to the nature of change brought about by the elements of uncertainty and mortality into the lived experience of being in the world as a cancer survivor. The importance of spirituality and prayer as areas of growth and exploration also was reported widely in the research literature on cancer survivorship (Dow et al.; Ferrans, 1994; Ferrell, 1996; Fredette; Vachon, 2001).

An important finding in this study was the nature of encounters with healthcare professionals. Some participants had new insights about the role of caring and compassion in treatment. Like the findings of Ferrans (1994), Ferrell and Dow (1996), and Pelusi (1997), caring providers were a source of comfort in very challenging situations. Halldorsdottir and Hamrin (1996) and Watson (1990) identified caring competencies, including being open and perceptive, having genuine concern, being truly present to the patient, and having the courage of involvement. The issue of uncaring providers is not cited often in the cancer research literature, nor are the consequences of such behaviors for patients. Halldorsdottir and Hamrin and Halldorsdottir (1996) found uncaring behaviors similar to this study: a focus on task instead of person, a lack of recognition of the individual, and the impact of behavior on the patient. Uncaring encounters create a sense of mistrust, disconnection, discouragement, and distress for patients. The participants in this study changed providers based on experiencing uncaring behaviors and were clear that such behaviors created distress and depleted energy needed for healing and well-being. Frank (1991), a sociologist and researcher of patients' experiences, commented on the energy required to manage a lack of sensitivity to the care needs of patients in his firsthand account of receiving chemotherapy. He and his wife did not tell their oncology nurse about their social support needs because they were not sure that she could bear their story and also because the setting did not give them the privacy they needed to share it. He was clear that such a strategy took energy that he needed to heal from his treatment. Caring practices in oncology care are health promoting, a means of conserving energy.

Limitations

Participants were self-selected and may not be representative of nurse cancer survivors. Conclusions cannot be generalized to the population of all nurses experiencing cancer, but the findings give pause for reflection on the nature of this experience for nurse colleagues. Also, the majority of participants were within five years of diagnosis. A future study might examine the experience for people further out from diagnosis. These participants were a homogeneous group, with only one Asian member. Future studies might examine other cultural groups or nurses from other geographic areas.

Implications for Nursing

The findings suggest the importance of identifying caring practice needs specific to nurse cancer survivors. Consideration of compassionate care directed to issues of control and expectations versus care realities is a key area for creative interventions directed toward nurses seeking to explore wellness and healing as cancer survivors. Consideration should be given to open and candid provider conversations about the shock of transitioning from a professional world to a personal world of cancer diagnosis and survival. Conversations should include addressing the issue of needing to have control over orchestrating care that may need to be transitioned to being cared for collaboratively. Thoughtful time needs to be given for provider and nurse patient reflection related to the relationship between positive ideals and memories of a nurse's own caregiving practices and what one actually receives in the healthcare system. Lastly, the findings suggest the importance of including conversations with nurse cancer survivors about their faith-based resources during treatment, as well as creating mechanisms to give honest feedback and guidance when nurse patients experience uncaring behaviors.

Conclusion

Nurse cancer survivors had a deep appreciation of the life-altering dimensions of this illness experience. They highly valued support to successfully navigate the survivorship process. Participants learned that caring behaviors in clinical encounters are subtle yet essential for health and well-being. The artificial boundary of the human world of the patient and that of the nurse was dismantled, allowing for a deeper appreciation of this lived experience. Survivorship presented an opportunity for change and reflection on quality of life. This knowledge can broaden clinicians' perspectives on the experiences and care needs of their nurse colleagues.

Author Contact: Rosanna F. DeMarco, PhD, APRN, BC, ACRN, can be reached at rosanna.demarco@bc.edu, with copy to editor at rose_mary@earthlink.net.

References

American Cancer Society. (2004). Statistics. Retrieved February 27, 2004, from http://www.cancer.org/docroot/NWS/content/NWS_2_1x_From_Survivor_to_Advocate_She_Lobbies_for_Early_Detection_Screening.asp

Auchincloss, S.S. (1995). After treatment. Psychological issues in gynecologic cancer survivorship. *Cancer*, 76(10 Suppl.), 2117–2124.

Breaden, K. (1997). Cancer and beyond: The question of survivorship. *Journal of Advanced Nursing*, 26, 978–984.

Buerhaus, P.I., Staiger, D.O., & Auerbach, D.I. (2000). Implications of an aging registered nurse workforce. *JAMA*, 283, 2948–2954.

Carter, B.J. (1989). Cancer survivorship: A topic for nursing research. Oncology Nursing Forum, 16, 435–437.

Carter, B.J. (1993). Long-term survivors of breast cancer. Cancer Nursing, 6, 354–361.

Dirksen, S.R. (1995). Search for meaning in long-term cancer survivors. *Journal of Advanced Nursing*, 21, 628–633.

Dow, K.H. (1990). The enduring seasons in survival. Oncology Nursing Forum, 17, 511–516.

Dow, K.H. (1991). The growing phenomenon of cancer survivorship. Jour-

nal of Professional Nursing, 7, 54-61.

Dow, K.H., Ferrell, B.R., Haberman, M.R., & Eaton, L. (1999). The meaning of quality of life in cancer survivorship. *Oncology Nursing Forum*, 26, 519–528.

Endo, E., Nitta, N., Inaayoshi, M., Saito, R., Takemura, K., Minegishi, H., et al. (2000). Pattern recognition as a caring partnership in families with cancer. *Journal of Advanced Nursing*, 32, 603–610.

Farmer, B.J., & Smith, E.D. (2002). Breast cancer survivorship: Are African American women considered? A concept analysis. *Oncology Nursing Forum*, 29, 779–787.

Ferrans, C.E. (1994). Quality of life through the eyes of survivors of breast cancer. *Oncology Nursing Forum*, 21, 1645–1651.

Ferrell, B.R. (1996). The quality of lives: 1,525 voices of cancer. *Oncology Nursing Forum*, 23, 909–916.

Ferrell, B.R., & Dow, K.H. (1996). Portraits of cancer survivorship: A glimpse through the lens of survivors' eyes. *Cancer Practice*, *4*, 76–80.

Ferszt, G., & Waldman, R. (1997). Psychosocial responses to disease and treatment. In C. Varricchio, M. Pierce, C. Walker, & T. Ades (Eds.), A

- cancer source book for nurses (7th ed., pp. 245-252). Sudbury, MA: Jones and Bartlett
- Frank, A. (1991). At the will of the body: Reflections on illness. Boston: Houghton Mifflin.
- Fredette, S.L. (1995). Breast cancer survivors: Concerns and coping. *Cancer Nursing*, 18, 35–46.
- Gambosi, J.R., & Ulreich, S. (1990). Recovering from cancer: A nursing intervention program recognizing survivorship. *Oncology Nursing Forum*, 17, 215–219.
- Halldorsdottir, S. (1996). Caring and uncaring encounters in nursing and healthcare—Developing a theory. Linkoping, Sweden: University of Linkoping.
- Halldorsdottir, S., & Hamrin, E. (1996). Experiencing existential changes: The lived experience of having cancer. *Cancer Nursing*, 19, 29–36.
- Hamilton, D. (1999). Points-of-no-return. Reflections, 25(4), 8-9.
- Harrell, H.C. (1972). To lose a breast. American Journal of Nursing, 72, 676–677.
- Is cancer different when you are a nurse? (1982). AORN Journal, 35, 1296–1302.
- Jonsdottir, H. (1998). Life patterns of people with chronic obstructive pulmonary disease: Isolation and being closed in. *Nursing Science Quarterly*, 11, 160–166.
- Kayser, K., Sormanti, M., & Strainchamps, E. (1999). Women coping with cancer: The influence of relationship factors on psychosocial adjustment. *Psychology of Women Quarterly*, 23, 725–739.
- Krause, K. (1991). Contracting cancer and coping with it. Patients' experiences. Cancer Nursing, 14, 240–245.
- Lamendola, F.P., & Newman, M.A. (1994). The paradox of HIV/AIDS as expanding consciousness. *Advances in Nursing Science*, 16(3), 13–21.
- Lee, C.O. (1997). Quality of life and breast cancer survivors. Psychosocial and treatment issues. *Cancer Practice*, 5, 309–316.
- Leigh, S. (1994). Cancer survivorship: A consumer movement. Seminars in Oncology, 21, 783–786.
- Leigh, S. (1999). Survivorship: What does it mean to nurses? *Innovations in Breast Cancer Care*, 4(2), 37–38.
- Leigh, S., Boyle, D.M., Loescher, L., & Hoffman, B. (1993). Psycho-social issues of long-term survival from adult cancer. In S. Groenwald, M. Frogge, M. Goodman, & C. Yarbro (Eds.), Cancer nursing: Principles and practice (3rd ed., pp. 485–495). Sudbury, MA: Jones and Bartlett.
- Leigh, S., Williams, J., & Stovall, E. (1998). Survivorship: From the moment of diagnosis. *Cancer*, 83, 1710–1713.
- Loescher, L.J., Clark, L., Atwood, J.R., Leigh, S., & Lamb, G. (1990). The impact of the cancer experience on long-term survivors. *Oncology Nurs*ing Forum, 17, 223–229.
- Moch, S.D. (1989). Health within illness: Conceptual evolution and practice possibilities. Advances in Nursing Science, 11(4), 23–31.
- Morse, J. (2000). Determining sample size. *Qualitative Health Research*, 10(1), 3–5.
- Nally, A.T. (1999, June). Nurse survivors face each new day with humor and

- hope. ONS News, 14(6), 1-5.
- National Coalition for Cancer Survivorship. (2002). National Coalition for Cancer Survivorship homepage. Retrieved February 27, 2004, from http:// www.canceradvocacy.org
- Newman, M. (1994). Health as expanding consciousness. New York: National League for Nursing.
- Newman, M.A. (1999). The rhythm of relating in a paradigm of wholeness. Image—The Journal of Nursing Scholarship, 31, 227–230.
- Newman, M.A., & Moch, S.D. (1991). Life patterns of persons with coronary heart disease. Nursing Science Quarterly, 4, 161–167.
- Ott, C. (1997). Culturally competent nursing care related to breast cancer. Nebraska Nurse, 30(3), 31.
- Pelusi, J. (1997). The lived experience of surviving breast cancer. Oncology Nursing Forum, 24, 1343–1353.
- Picard, C., Agretelis, J., & DeMarco, R. (2004). Using reflective art and text to convey appreciation of pattern with nurse cancer survivors. Unpublished manuscript.
- Scannell, E.A. (1985). "I've seen cancer from both sides now": A clinical nurse specialist shares her own cancer experience. *Cancer Nursing*, 8, 238–245.
- Simon, M.A. (1978). No one should face cancer alone—Not even a nurse. RN, 41(3), 79, 84, 86.
- Utley, R. (1999). The evolving meaning of cancer for long-term survivors of breast cancer. Oncology Nursing Forum, 26, 1519–1523.
- Vachon, M.L. (2001). The meaning of illness to a long-term survivor. Seminars in Oncology Nursing, 17, 279–283.
- Van Manen, M. (1990). Researching lived experience: Human science for an action sensitive pedagogy. Albany, NY: State University of New York Press
- Watson, J. (1990). Postmodern nursing and beyond. London: Churchill Livingstone.

For more information . . .

- ➤ Coalition for Cancer Survivorship www.canceradvocacy.org
- ➤ Cancer Survivors Network www.acscsn.org/?popup=1
- ➤ National Cancer Survivors Day www.ncsdf.org
- ➤ New England Coalition of Cancer Survivorships www.neccs.org

Links can be found at www.ons.org.