

Nurse Experiences as Cancer Survivors: Part II—Professional

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Purpose/Objectives: To uncover dimensions of nurses' professional 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. Data were analyzed using the methodology of Newman (1994, 1999) and VanManen (1990).

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

Findings: Professional experiences of cancer survivorship fell into five themes: (a) role ambiguity, (b) a deepening level of compassion for patients and others, (c) self-disclosure as a therapeutic intervention, (d) becoming an advocate for change, and (e) volunteerism.

Conclusions: Cancer survivorship was a factor in reshaping participants' clinical practice. Experiencing the role of the patient affirmed the necessity of compassionate care for these participants. Nurses experienced a deepening level of compassion for patients and used self-disclosure as a therapeutic intervention. During and shortly after treatment, role ambiguity (being both patient and nurse) could cause difficulties. Nurses took action to change their clinical environment through their influence on colleagues and the healthcare system and by working through other organizations to improve patient care.

Implications for Nursing: Nurse cancer survivors can benefit from the support of colleagues and healthcare providers and an appreciation of the challenge of being both a professional and a patient. The invitation for dialogue as they return to work may help with the challenges of role ambiguity as nurse cancer survivors. Based on this study, nurses value the opportunity to enhance care environments with their two-world knowledge through compassionate care, disclosure, advocacy, and volunteering, and coworkers need to appreciate each nurse's unique response to this potentially life-changing process. Nurses in all settings can learn from their cancer survivor colleagues who have been the recipients of care to reflect on their own clinical practice in the areas of advocacy, sensitivity to patient concerns, and care experiences.

Before you know what kindness really is, you must lose things, feel the future dissolve in a moment like salt in a weakened broth.

—N.S. Nye (1998, p. 42)

When nurses are diagnosed with cancer, the process of their survivorship is one of living in two worlds, that of patient and provider. The healthcare community is responsible for investigating and responding to the needs of its colleagues, in this case, nurses. Cancer is a chronic disease, and many nurses return to work either during or after their

Key Points . . .

- ▶ Nurses' professional practice has changed as a result of experiencing cancer and its treatment.
- ▶ Balancing work and treatment is best supported by coworker sensitivity to each nurse's unique needs.
- ▶ Healthcare professionals can learn from cancer survivor colleagues about ways to improve clinical practice.

treatment. Nurse survivors hold positions as dual insiders—patients and healthcare professionals. The aim of this research study was to uncover the dimensions of nurses' experiences related to cancer survivorship. The findings and discussion in this article address the second question of the study, the effect of the illness on a nurse's professional life. Engaging nurses in this inquiry may provide a deeper understanding of the needs of nurses who are also patients.

Literature Review

Accounts of the impact of cancer survivorship on nurses' professional practice have been limited to anecdotal reports with a focus on the personal nature of the experience and some advice for nurses on patient needs (Fedora, 1985; Hamilton, 1999; Leigh, 1992; Vachon, 2001). Nally (1999) reported that two nurse cancer survivors identified that the experience made them better nurses by helping them to be more present and compassionate with patients. Simon (1978) found that working as a nurse caused her distress prior to diagnosis but the support of a supervisor helped her to transition back to practice following

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Digital Object Identifier: 10.1188/04.ONF.537-542

treatment. She found that the experience helped her to become more confident, an attribute she could share with her patients. As an oncology clinical specialist, Scannell (1985) found that, because of her cancer diagnosis and treatment, she came to appreciate the uniqueness of each individual's response to the illness and the important role she could play in helping patients to cope.

As healthcare professionals, nurses live in a complex world where the intensity of the work may present challenges during their own treatment for cancer. Also, an insider's perspective as a recipient of care may influence a nurse's subsequent practice. No published studies explore nurses' cancer survivorship and its impact on their professional practice. Also, the knowledge that survivorship brings may have implications for oncology clinical practice.

Methods

Design

A qualitative phenomenologic design was selected to explore the professional experience of cancer survivorship among nurses. The study design is based on Watson's (1999) caring theory and Newman's (1994) theory of health as expanding consciousness. The researchers believed that caring is an essential component of this form of research. Rather than a dispassionate stance for the researcher, caring is a form of engagement and full presence to listen to the stories of participants. The researchers employed a method of cooperative inquiry developed by Newman (1994), who believed that inviting a person's story will uncover a pattern of what is most meaningful. The outcomes of this research can take the form of self-awareness and insight for participants and knowledge for the professional community. Newman (1999) challenged the somewhat artificial distinction between research and practice when engaging in this form of inquiry. In this study, the participants engaged with the researchers to examine their cancer survivorship and to reflect on their stories in a series of two in-depth interviews. The researchers included a psychiatric clinical specialist who was also the methodologist, an oncology clinical specialist, and a nurse cancer survivor.

Data Collection and Analysis

Each participant was interviewed twice either in the researchers' offices or at the homes of participants, depending on participant preference. Interviews lasted from 50 minutes to two hours. Each participant saw the same researcher for both interviews. All interviews were tape recorded and transcribed. In the first interview, participants could answer the research question. Participants were invited to share writings or other modes of expression with the researchers as well, and a few of the participants shared journal writings. Based on examination of the transcripts and any other writings shared by participants, the researchers constructed a narrative over time of the key elements of each person's story. During the second interview, the researcher shared her understanding in writing, using the participant's own words, and in a piece of reflective artwork that the researcher 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 reflect on, edit, clarify, or expand on their stories. After data collection, researchers exam-

ined all texts, including transcripts of the first and second interviews and the narrative text shared with participants. A detailed line-by-line examination of all data based on VanManen's (1990) approach identified sentences or phrases that captured dimensions of the experience. All researchers examined transcripts separately. Statements were coded to identify elements of the cancer experience that affected the nurses' professional role. These elements were categorized into themes as the three researchers examined the data folders together. The emergent themes were based on data found in at least 75% of the participant stories. The team addressed any differences in impressions of elements in the data until consensus was reached.

Findings

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. A total of 50 interviews were conducted, or two per participant. Interviews lasted from 50 minutes to two hours, with the average being 60 minutes. Previous studies using this method confirm the adequacy of the sample size for this study design (Endo et al., 2000; Jonsdottir, 1998; Lamendola & Newman, 1994; Newman & Moch, 1991). Of the 25 RNs participating in the study, 23 were women. The total sample ranged in age from 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 participants ($n = 20$) were within five years of diagnosis. Cancer types and sites varied and included 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.

The professional experiences of cancer survivorship included (a) role ambiguity, (b) a deepening level of compassion for patients and others, (c) self-disclosure as a therapeutic intervention, (d) becoming an advocate for change, and (e) volunteerism.

Role Ambiguity

Once those who needed surgery had received it, the majority of nurses worked during their treatment, often scheduling treatments close to the weekend as a strategy to maintain structure and a sense of ordinary routine during the work week. Working meant feeling strong, competent, and in control of their professional lives. But the diagnosis and treatment of cancer challenged this position of strength and control. Although working was a way of maintaining normalcy, the experience of being in another world as a patient was never far away. In fact, 14 nurses were treated in their own hospitals. This provided convenience but also could be a challenge as the roles of patient and nurse merged.

I would feel most unsettled; I would walk in and see somebody that was a caretaker [her oncology provider],

who was very giving, and then they would make me feel settled, and well, then why do you feel this way? I guess ambiguousness about my role. Who was I? When I would walk through the door every day at [the hospital], I had the impression or impact of . . . what am I? Am I patient or am I a nurse?

Some nurses would take paperwork from their professional positions to complete while receiving infusion treatments or waiting for radiation. One expert oncology nurse worked in the infusion center of her hospital and mixed her own chemotherapy. In retrospect, she decided this was not the best thing to do.

I'd have it in one of the treatment rooms and then I'd get up and go in and continue to treat the other people there . . . because I'm a patient in my own clinic. I'm pretty much my own nurse also . . . I probably should have been in a more dependent role, but . . . that's just not what happened. I think you're very anxious to get back to, you know. You want to do all that you can for yourself so that you're not dependent.

Even for those not treated in their own institutions, role ambiguity and the energy needed to manage treatment and work could sometimes exceed their resources. As one nurse said, "The feedback from work was—I was like a robot. I just became so mechanical, and I didn't realize. I thought I was coping fine." Generally, keeping a focus on their professional lives was a way of coping. They valued their work for its intrinsic value and as a distraction. Their professional role was a barrier to being solely defined by this illness.

Why would you want to sit home and dwell on it? It would have done a job on me. I'm sure. Better go to work and just keep active and talk, and that's what people said, that I hid it really well. It isn't even that I don't think I hid it—I just put it out of my mind.

In retrospect, many nurses acknowledged that they struggled with role ambiguity. They valued their professional role but wished they had taken more time for themselves. The relationships with coworkers and managers varied. Some participants had difficulty discussing their illness with coworkers, even though other nurses expressed interest and a wish to help. They needed to distance themselves from coworkers' inquiries and maintain a sense of privacy to retain their composure during the workday. For most, the interactions with coworkers were supportive. The role ambiguity could be difficult to express to others, particularly to those who had never been treated for a serious illness. As one participant said, "There is an adjustment period when you go back to work. . . . It's really hard to explain."

Deepening of Compassion for Patients and Others

Although the nurses described themselves as caring practitioners prior to their illness, having their own experience as patients deepened nurses' sense of compassion for their own patients, family members, and coworkers. They used the language of compassion and understanding to describe the change in their practice.

To me, being the patient was dramatic. When you're the patient, [you know] how you want to be treated, and you treat others like that. I always treated people like I always

thought I wanted to be treated, but after I was actually the patient, then you *know*.

These nurses could place themselves in the situation of the patient with more ease. Compassion involved becoming better listeners, taking time for a patient's story, and individualizing care. One nurse articulated the approach she now took in her practice of becoming a more astute listener and appreciating patients' agendas in clinical situations.

[I ask patients,] "What are you most afraid of? What are your biggest concerns?" . . . My patients would come in with their issues, and I think there are priorities, but I have to hear their priorities first.

An intensive care nurse reported that she attends to families with a deeper appreciation and compassion. She does find that coworkers do not always have her perspective. "Sometimes, the nurses call me and complain that there are eight people in [the patient's] room. . . . I tell them, if you have a loving family, let's use that as therapy."

Participants acknowledged that having cancer heightened their sense of compassion and that other nurses might not have this awareness. "I think that some nurses really shortchange the emotional aspect of this. And, you know, I might have been one of them [before diagnosis]." Another participant remembered working in the emergency department and caring for patients with cancer who were dehydrated and focusing on the medical intervention. He now appreciates the need for attention to the person, "to ask, what is going on with your treatment? Just to acknowledge you have no hair on your head. Just an option to talk about it."

Participants also shared that they offered a compassionate presence to coworkers who were struggling with their own illnesses or those of family members, understanding that offering some form of support helps others to get through such difficult situations. They expressed their support in the form of conversation or sending notecards.

Self-Disclosure as a Therapeutic Intervention

Many nurses shared their diagnosis with patients, either because they decided it was the right thing to do to help patients or because colleagues suggested that they do so. They carefully weighed this decision based on its potential therapeutic benefit to patients. Expressing emotion with patients also was part of the disclosure.

So there were some parallels there that we had, but she just would grab my hand on the way to the OR [operating room] and she said, "I'm gonna make it like you." Now, as a nurse and as a human being and a cancer survivor, you want somebody to go under anesthesia with that in their head . . . and so, depending on the situation, sometimes I can share it. You get a gut feeling when to do it and when not to do it.

The participants wanted to make the decision to disclose on their own, and they made it clear to colleagues that they would choose when disclosure was appropriate. Although self-disclosure frequently was cited as positive, nurses could not do it without some feelings of discomfort about role ambiguity. Each disclosure also functioned as a reminder of the two-world experience while working as a nurse.

Advocacy

Having cancer changed participants' views of the healthcare system and their role within it. They began to think of patient care from a wider perspective than the direct care they provided and took action to change policies, protocols, and the care environment. They frequently became identified in their own institutions as a resource person to call for advice or consultation on patients with cancer. They would offer to speak with patients who were newly diagnosed and trying to decide on treatment options.

Many reported that, prior to their illness, they did not have the nature or personality style to be a public advocate but having cancer became a call to another form of service. One nurse became involved in safe staffing-level negotiations, a new experience for her and one that she believed was essential to ensure quality care for her patients. Another nurse had a research protocol changed after her experience with 12 breast biopsies without adequate pain management.

But I think it gave me that strong voice to say, okay, patients need to be taken care of and we have to do what's right for the patients. I wasn't always that strong in nursing issues, like, okay, somebody open doors, you know; it's given me that strength.

Another participant who had a port catheter removed because it had lodged in her ventricle was given nothing for pain. She challenged her physician to change his practice.

It was horrible. . . . I realize now, medicate people! Medicate them. Why would you not? What are you going to do to them? I understand why you don't medicate a patient who's having chest pain right away. You want to figure out things.

Nurses also created dialogue with colleagues about their experience as a way to advocate for better caring practices. One nurse talked with a colleague who had just begun working in an oncology infusion unit and who did not consider her present work as important as work in a previous care setting.

She's used to doing floor nursing, and this is just, like, kind of a minor thing. And I kept trying to tell her, give it a chance. You don't know how important you are to that patient. Because they're gonna get through a treatment because of you. Because of you!

Advocacy also involved creating resources when they were not available. A participant who struggled with postsurgical lymphedema decided to challenge the healthcare community to examine the problem. She also created a support group and electronic information center for people with lymphedema in New England. She used her access as an oncology nurse to seek out experts and resources on the topic and planned a national conference on the issue of lymphedema treatment and research.

Volunteerism

With few exceptions, all of the nurses interviewed saw the merit in sharing their expertise as both patients and nurses by becoming involved in volunteer groups. The nurses described donating specific services to patients with cancer, fund-raising for cancer care and research, or giving time in an advisory capacity to cancer care organizations, foundations, and boards (e.g., working with the American Cancer Society, running

support groups, participating in fund-raising walks, doing parish or hospice nursing, serving on patient advisory councils in healthcare institutions). Many described how giving support as a volunteer emanated from their own discovery of the value of others providing support to them during their own survivorship. Their volunteering efforts gave to others but also was a reciprocal process because the nurses benefited from their service.

I've been volunteering. I never did that before. I speak to other women that are going to contemplate the surgery—[breast] reconstruction, and I show it to them—show the families. I'm very open about it, and I show people about it, and they seem to really . . . be more comfortable after the surgery. They've seen it, know what to expect, and talked to someone that's had it. That makes me feel good when I do that.

Participating in the study also was identified as a form of volunteerism because the nurses wanted to contribute their stories to help colleagues appreciate cancer survivorship. They reported that they responded to the study advertisement because they wanted to contribute to nursing research and believed that their stories could have a wider impact on practice as part of the study.

Discussion and Practice Implications

Becoming a cancer survivor changed the professional lives of these nurses. Their own care needs and experiences shaped their appreciation of and obligation to others. They want their experience to make a difference in the care of others. Frank (2002) posed the challenge to healthcare professionals to create a space for the "remoralization" of people who are illness survivors. Remoralization is the process of reflecting on one's moral obligation to society. Frank believed that survivors of life-threatening illnesses need to teach others what they have learned. These nurses considered the experience one that, with rare exception, had to be shared with nurse colleagues to change health care. They also disclosed their illness to patients so they would not feel alone on their journey. The dialogue is a reciprocal process. These nurses found their compassionate approach to care something that also changed themselves. Their stories are a form of clinical evidence to be witnessed and appreciated. The actions of the nurse participants are examples of what Frank calls extensive responsibility, where the nurses were very active in contributing to change the situation for others, by volunteerism, advocacy, and shaping their practice and their work environments.

Can coworkers develop a deepening compassion based on the new wisdom from their cancer survivor colleagues? Or do they need a life-threatening illness of their own to deepen their compassion? These nurses invited nurse colleagues in all clinical settings to appreciate the value of compassionate care by recognizing human vulnerability through their stories. The boundary between professionals and patients in healthcare is, in some respects, artificial, particularly when considering the impact of a life-threatening illness such as cancer. Perhaps the illusion of the patient as "other" can create a barrier of false protection from personal vulnerability. The nurses in this study make the case for recognizing that this boundary does not exist—everyone is potentially in this vulnerable position. If nurses are open to examining the vulnerability inherent in

being human, they can reflect on a patient's story as a version of the human story in which nurses participate. "It is looking into the transformative mirror and seeing oneself as that suffering person at some other time, past or future" (Picard, Sickel, & Natale, 1998, p. 30). A compassionate interpersonal connection was a lifeline that helped these nurses to get through treatment, and they were able to apply this knowledge to their professional practice. They invited their colleagues and providers to do the same.

The finding of role ambiguity is a cause for concern in terms of well-being of nurse cancer survivors. Oncology nurses caring for nurse patients might engage them in dialogue about their professional role. The struggle with role ambiguity might be lessened by social support. Oncology nurses and colleagues of nurse cancer survivors must consider that each person is unique in his or her response to the illness and support needs during and after treatment. Rather than anticipating what will be most helpful, nurses should inquire about what kind of support is desired. For example, engaging in lengthy or ongoing discussions while at work may not be helpful during diagnosis and treatment, but notes or after-work conversations may be appreciated. As one participant shared, she did not want to discuss her laboratory results with coworkers during regular work hours. She needed to get through the day. Stewart (1993) defined social support as "interactions with family members, friends, peers, and healthcare providers that communicate information, esteem, aid, and reliable alliance" (p. 14). The literature indicates that social support can make a difference in the illness experience (Northouse, 1988; Stewart & Tilden, 1995). These interactions can help nurses to cope and promote health during their recovery period. Human resources or oncology services might consider offering a support group for nurses and other healthcare professionals returning to work as another means of providing social support. Because the balance of work and treatment may be challenging but important to overall coping, nurse managers must appreciate and support the value of working as these participants have articulated.

Other researchers have reported on volunteerism and advocacy as dimensions of survivorship (Dow, Ferrell, Haberman, & Eaton, 1999; Ferrans, 1994; Pelusi, 1997; Taylor, 2000). These nurses, however, held an added advantage in creating change. They had insider knowledge on how to change policy

or procedures. Also, their position as nurses and patients lends some authority to their perspective on patient needs. The participants expressed value in volunteering as a way to create change beyond the walls of their institutions and offered an invitation to nurse colleagues to reexamine their own professional roles in health care. Healthcare professionals can support nurse cancer survivors by inviting their participation in changing care practices.

Directions for Future Research

Future study might examine the relationship of social support to the experience of recovery, role ambiguity, and quality of life of nurse cancer survivors. Also, because the majority of the participants were within five years of diagnosis, a future study might examine the experience for people further out from their diagnosis. Also, the participants were a homogeneous group, with only one Asian member. Future studies need to examine other cultural groups and nurses from other areas or countries.

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.

Conclusion

Cancer survivorship was a factor in shaping participants' clinical practice. They took action to improve their clinical environment through their compassionate care of patients and influence on colleagues, on their healthcare systems, and by work through other organizations. Working while in treatment can be challenging, but working was a valued activity to feel in control and not defined solely by the illness experience. Nurses can benefit from the support of treatment providers, coworkers, and managers during their treatment experience, when the two-world experience is closest.

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For more information . . .

- ▶ National Cancer Survivors Day
www.ncsdf.org
- ▶ Cancer Control and Population Sciences: Office of Cancer Survivorship
http://dccps.nci.nih.gov/ocs
- ▶ New England Coalition for Cancer Survivorship
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Oncology Nursing Society 30th Annual Congress April 28–May 1, 2005, Orlando, FL

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