

Three Little Words No One Wants to Hear

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Romantics would agree that the three little words everyone wants to hear are, “I love you.” I heard the opposite of those words in June of 1999 when my doctor told me, “You have cancer.” A cancer diagnosis is a terrifying experience for anyone. Questions such as, “Why me?” “Why now?” “What did I do wrong?” “Could this have been prevented?” and “Is this a mistake?” commonly race through your head.

This article describes an examination of a personal experience with cancer in conjunction with cancer experiences represented in the nursing literature and those of oncology nursing colleagues with respect to these questions: How does the cancer experience differ when patients are oncology nurses, specially trained in the prevention, detection, and treatment of cancer? Does this proficient knowledge make the cancer experience more or less frightening? Will the nurses avail themselves of all the resources available—the same resources they would advise patients to take advantage of?

Although oncology nurses may be expected to be less fearful of a cancer diagnosis because they are more familiar with the disease, I, as well as others described in the literature, had a different experience (Tosh-Kennedy, 2007). Oncology nurses have the same emotions as their patients: anger, dismay, and disbelief; however, the emotion they may feel more acutely than patients is guilt. As a cancer specialist, I felt guilty because I thought I should have known earlier, sensed something was wrong before my doctor did, or sought earlier consultation. Although I am pleased to be a survivor, I have felt guilty for surviving.

My Story

Some dates become etched in our memories—the first day of school, your

wedding day, and the date you are told you have cancer. For me, that day was June 11, 1999. The spring of 1999 was stressful for me. I had taken longer than expected to bounce back from a virus that had left me fatigued. On top of this slow recovery, I thought the onset of mid-cycle bleeding was a first symptom of perimenopause.

As a nurse, I thought about the symptoms of menopause and realized that, aside from the breakthrough bleeding, I did not have accompanying symptoms such as hot flashes, mood swings, or vaginal dryness (National Library of Medicine, n.d.). I decided to see my family doctor for a consultation. I was not too worried because my recent annual checkup was fine, including my Pap smear, and I did not have any of the common risk factors for serious illness.

After my physician and I discussed my symptoms, she said I had “nothing to worry about,” and we should wait to see what developed. I asked her if she would examine me, and she informed me that I had a polyp that was causing the bleeding. “I know you are worried about it, the doctor said, “and I can tell you—this isn’t cancer.” I was relieved. The doctor recommended waiting and cautioned against a referral to a gynecologist, thinking I would undergo an unnecessary surgical procedure, such as a dilation and curettage or hysteroscopy.

After another four weeks with no change in bleeding, I decided to see a gynecologist. Although reluctant, my physician agreed to send a referral, and I was seen within one week. The gynecologist

performed a hasty examination and sent a Pap smear to the laboratory. He told me that I would be booked immediately for a dilation and curettage and hysteroscopy because “there have to be some perks for healthcare workers and moving up a surgery date should be one of them.” I was happy but also felt guilty about the early surgery date.

One week after my visit, I received a phone call at work. A receptionist from my gynecologist’s office told me I had been booked to see another gynecologist for a colposcopy on June 11th. I questioned this appointment, wondering why I would be seeing someone other than my gynecologist. She patiently answered that the Pap smear revealed a cervical intraepithelial neoplasia, grade III (CIN III). Because those results always prompted a colposcopy to have a closer look at the cervix and, because my gynecologist did not perform colposcopies, I had an appointment scheduled with the other physician. “CIN III just means you have some abnormal cells,” she said, “it isn’t cancer.” Although, I knew she was trying to allay my fears, I hotly replied, “Do you realize that you called me at work, and I work at the cancer center? I know very well what CIN III means, and it may well be cancer and, at the very least, it is decidedly worrisome.”

I attended the colposcopy appointment by myself, even though my husband had volunteered to come with me, because I was trying to keep him from worrying. Once I had checked in for my procedure, I asked the receptionist if I could see my report. I was in such denial at the time,

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I was certain I would find the report belonged to another unfortunate person. Try as I might to find a discrepancy, no errors existed.

During the appointment, the doctor had an obstetrical gynecology resident examine me with my permission. After the resident inserted the speculum, I immediately noticed the look of shock on her face and knew something was wrong. The resident tried to be positive and talked to me about how easily she could visualize my cervix. She went on to explain that the last time she had used the device, she had difficulty visualizing the cervix of that patient. Her words, however, could not disguise the look on her face or the urgency with which she wished to pass

great professionalism he merely shook his head and told me he would send her a letter outlining what the plan would be.

Somehow, I made it back to work at the cancer center. Within 30 minutes, I had not only made a tearful phone call to my husband, but everyone who I worked with knew the bad news. My colleagues and friends rallied to my side and, by the end of the day, my job had been handed over to another nurse, and I had the option to work or not as I saw fit.

Arrangements were made to have my pre-operative physical performed by a clinic associate whom I respected and trusted, and my nurse manager called people in the health region to see if an earlier surgical date was available. I had a

computed tomography scan and an IV pyelogram to examine my kidneys, a chest x-ray, and blood work, and began the long wait for July 12. Other surgeons were willing to give up time in the operating room (OR) for an earlier

surgery date, but, unfortunately, doctor could not change his holiday plans.

About a week later, I received a phone call from my family physician. She apologized for not calling sooner and explained that she had been out of town with her family. She expressed her dismay at hearing my diagnosis and, of course, concern for my well-being. She would see me for my pre-operative assessment any time that it suited me. I told her everything that needed to be done prior to surgery had been done, and all that was left was the waiting. I hesitated when she asked me if I wanted her to be there for the surgery. After considering my feelings, I decided it was probably best to have all my resources available.

I woke up at 4:30 am on July 12 to a beautiful sunrise. I did what I could to ensure that everything was in place for the time I would spend in the hospital, postoperatively. Looking back, it seems ironic that I was so concerned about putting the house in order when I felt as though my life was in complete disorder. I kissed my sleeping children and told them that no matter what happened, I loved them. I hugged and gave a treat to our dog, and I left the house with my husband. We met my brother, who had been

a pillar of strength for both my husband and me during this time, at the hospital. My preoperative nurse was a friend with whom I had worked a few years previously. Her concern and assurance gave me great comfort as I walked down the corridor to the operating room.

I have intermittent memories of the rest of that day, from the arrival of the doctor to seeing my husband's teary, relieved face when I arrived in intensive care, to throwing up when I took my first self-administered shot of morphine through the patient-controlled analgesic pump.

My convalescence was relatively uneventful, thanks to the help and support of my family and co-workers, and I was fortunate that I did not require any treatment other than surgery. Now, eight years later, the only reminders I have of this incident are a long white scar on my abdomen, two more scars where my Jackson-Pratt drains resided on either side of the longer scar and, of course, the memories.

Experiences Shared in the Literature

I believe that, at least to some degree, my recuperation is similar to Leigh (1992, p. 1477) who stated that, "my physical recovery from treatment for Hodgkin's disease took about six months, but my psychological, emotional, and social recovery took years." Physically, I recovered from the surgery within six weeks, but the emotional trauma of the cancer diagnosis lingered long after the scars had healed. Leigh also discussed the susceptibility of cancer survivors to lose the ability to filter normal physical processes from a cancer recurrence, something with which I can readily relate. Every time I had a twinge of pain, experienced a change in bowel habits, felt more fatigued, or met new patients who described their symptoms prior to diagnoses (which mimicked my own), I was certain that the cancer had recurred.

Since then I have had plenty of opportunity to reflect on that period of my life. McEwen (2002), in a discussion of Mishel's Theory of Uncertainty, acknowledged that anxiety related to the disease or recurrence may never be resolved but, over time, may become part of a new paradigm for the cancer survivor. Frank (1991) expressed that a diagnosis of can-

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the camera over to the doctor for his experienced opinion. The doctor laid his hand on my knee and, with great concern, told me he was certain this was cancer but, just to be sure, he would send off a biopsy to confirm his suspicion. At that moment I felt what Frank (1991) described when he was told he had cancer—that my future had been taken away from me. I thought "I will never be able to hold my grandchildren in my arms."

Once the biopsy had been prepared for transport to the pathology laboratory, the doctor wanted to discuss a plan with me.

I had a hard time pulling myself together; tears were streaming down my cheeks, and my hands were shaking. The doctor's plan was that, if the biopsy came back positive (and he was certain it would), I would be scheduled for a radical hysterectomy. Because the surgery would be at least six hours and the doctor was going on vacation, my surgery was scheduled for July 12, 1999, another day that I will remember always. The doctor interviewed me about my general health, date of my last Pap smear, my last visit with my family physician. He bristled a bit when I disclosed that I had sought an opinion and referral from my family physician and had been told not to worry so much. With

cer affords people the chance to pursue something they always may have wanted to become rather than returning to the place they were before the diagnosis. I know that my experience has changed me as a person as well as a nurse. I now have a better understanding of my patient's frustrations, fears, and anger in the system during treatment. For me, at least for now, my cancer journey is at a halt, and I acknowledge that the outcome for some of my nursing friends and colleagues has not been as positive as my own.

I became curious about how the cancer experience differs for oncology nurses, especially those treated in the facilities where they have spent so much time caring for other patients with cancer. Con-salvo et al. (2007), I discovered, found few articles about nurses who are cancer survivors. In one, I was surprised to read that Clarke (2006), a nurse who was involved in clinical governance and practice development in Wales, was reluctant to explore the Internet for information about her cancer diagnosis, treatment, and prognosis. She expressed concern about finding conflicting information that would affect how she thought about her diagnosis. Although I can identify with her need to insulate herself from negative information, the behavior is contrary to what I have encountered with many patients who used the Internet to gather facts regarding their diagnosis as a way to make sense of the disease and regain control of their situation.

In retrospect, Clarke (2006) recognized that this refusal to self-educate demonstrated a weakness that was not apparent in her professional life. As a health professional and lecturer, Clarke prided herself in being able to search the literature for evidence. Yet, in her patient role, she was unwilling to arm herself with information. Her radiation therapy experience was terrifying for her until one therapist recognized that Clarke was "blocking" and endeavoured to teach her about her treatment as though she was a radiation therapy student embarking on a training program. By opening herself to this approach, reading the material provided to her by the therapist, and researching the suggested Internet sites, the rest of her therapy was less stressful for her.

Willette (1997), a nurse educator, also has discussed the difficulty she had dur-

ing her surgery for breast cancer. She saw her patient role as one that combined all the facets of who she was, including a "nurse, mother, wife, sister, daughter, friend, child, instructor, and woman" (p. 52). Initially, this complex collection of her many roles led to confusion for her as a patient. In short, she felt she had to face the journey alone because no one else possibly could understand what she was going through. However, throughout her journey as a patient with cancer, Willette experienced the "patient role" and began to lean on the nurses caring for her and subsequently learned, as I did from my journey, the real meaning of sympathy for what her patients faced each day.

DeMarco, Picard, and Agretelis (2004), an assistant professor of nursing who had ovarian cancer, a nursing professor, and an oncology nurse manager, respectively, examined the personal experiences of cancer survivorship in nurses. Although the researchers for this study did not focus solely on oncology nurses, they explored how a cancer diagnosis changes the personal and professional lives of nurses in general. The authors recognized that, despite of having professional knowledge regarding a cancer diagnosis, the nurses in the study experienced the same shock and disbelief as lay people. In the second part of their research project, Picard, Agretelis, and DeMarco (2004) reported that nurses wanted to maintain a degree of normalcy because their professional roles contributed to role ambiguity—were they patients or nurses? This was especially pronounced when they were treated in the same facility where they worked. Further, Picard et al. discovered that for

the nurses in the study, the idea of disclosing their own cancer diagnosis to their patients in a professional capacity was initially uncomfortable. Yet, later on, the nurses discovered that sharing their experience was therapeutic for their patients and themselves. The nurse participants all expressed how their cancer experiences enhanced their ability to be more sympathetic and in tune with their patient's needs. In addition, they were afforded the opportunity to develop

and change their approach to improve patient care by using their first-hand perspective. I still carefully consider which patients I share my cancer experience with because I am uncertain whether the information will be comforting or burdensome, but I do agree that my own first-hand experience has changed my approach to patient care.

Leigh (2006), also a nurse, has written about her personal experiences by reflecting on her long and arduous journey with cancer. She was diagnosed with Hodgkin disease in 1972. In her first reflections at the time, she wrote of feeling that other nurses were avoiding her, perhaps because they were uncomfortable caring for her. Her cancer experience drew her to the field of oncology and, after recovering from treatment, she embarked on a career change. Following her initial diagnosis, she was treated subsequently for breast and bladder cancer, thought to have resulted from her Hodgkin treatment. In addition, she experienced various other health conditions related to her cancer therapy. As a survivor, Leigh discovered that one of the most difficult things to deal with was survivor's guilt.

Unlike Leigh (2006), I always have felt that nurses do not choose oncology as a field of practice, but rather, oncology chooses them. I have witnessed many

Despite having professional knowledge and training about cancer, oncology nurses often experience the same shock and disbelief as lay people. As I discovered during my cancer journey, knowledge of cancer did not prepare me for nor soften the blow of hearing the words, "You have cancer."

nurses try on oncology nursing, but many find the fit not to their liking. Those who stay in oncology may find, as Perry (2006) suggested, that their role as an oncology nurse "leaves an imprint on many lives and, most likely, you are, in turn, being changed by the care-giving experience" (p. 37). Jackson (2004) stated that becoming engaged with patients provides professional and personal enrichment for the nurse while giving support and protection for patients and their fami-

lies. I believe that because of the close ties between oncology nurses and their patients, nurses may be reluctant to use resources available to all patients with cancer, and as healthcare professionals, oncology nurses may not join support groups or be willing to attend teaching sessions to avoid upsetting those patients. Unwillingness to jeopardize their patients' well-being may have a significantly negative impact on the cancer journey of oncology nurses because they may navigate the system on their own rather than tapping into available supports.

Closer to Home

Since I have experienced my own personal journey, I have recognized that my story was not unique. Two of my colleagues, both long-time oncology nurses, have faced their own battles. I have reflected on our stories—the similarities and the unique experiences. The first colleague, who was diagnosed in 2001, succumbed to her disease. Her colleagues were happy to be able to help her through her treatment in whatever way we could—establishing her IV in one try, rearranging her appointments to suit her new routine, and, most importantly, offering emotional support to her and her family. I was saddened for her family and all of us who knew her as a friend, but I was surprised to realize that a familiar emotion, guilt, was back. This time, I was not feeling guilty for failing to recognize a diagnosis when it presented itself, but rather, like Leigh (2006), I was feeling what I can only describe as survivor's guilt. This is something that I previously had recognized in many of the patients with whom I interacted who survived while other patients did not.

More recently, another colleague required treatment in the place where she devoted most of her nursing career. She has faced her diagnosis and treatment without complaint, accepting each new treatment offered to obtain a response where previous treatments had failed. When I think of our separate journeys, I recognize how blessed I am to have survived my ordeal. Although I feel great sorrow for my co-worker and her family, and pray that whatever lays ahead for them will be peaceful, I no longer feel guilt. Perhaps this is reflective of my age, or the number of years that have passed since

my own diagnosis, but I am relieved that I have been able to set aside my feelings of guilt for being human and for surviving.

Conclusion

Literature that specifically addresses the issue of a cancer diagnosis and treatment from the lived experience and perspectives of oncology nurses is prevalent. Nurses not employed in oncology experience fear and uncertainty when given their diagnosis. One might imagine that the experience would be just as terrifying for an oncology nurse as a nurse in any other field, despite specialized knowledge and training. As I discovered during my own cancer journey, my extensive knowledge of cancer did not prepare me for nor soften the blow of hearing the words “you have cancer.”

Consalvo et al. (2007) reported that the average age of nurses is increasing. Because the risk of cancer increases with age, more nurses will become patients with cancer or be faced with caring for one or more of our associates. As oncology nurses, I believe that it is prudent to consider how this experience for our colleagues may be different from other patients for whom we provide treatment. In addition, I recognize the importance of remembering that many parts of an oncology nurse's journey with cancer may well parallel those of other patients. Although they may not be comfortable initially asking for help from people with whom they have worked, oncology nurses need to give themselves permission to be patients and not professionals. This message is particularly important for all nurses and other healthcare professionals, who must keep in mind that despite their nursing background, they are patients with cancer, and, as such, need all the assistance and support other patients need. In addition, I suspect that nurses may need to be persuaded or encouraged to set the parameters for discussions to preserve their sense of control.

Since my cancer experience, many people have asked me how I can work where I do because I deal with cancer every day. My answer is simple. I believe that I have a richer understanding of the emotions patients are experiencing than I did before my own diagnosis and trust that this insight enables me to provide

more compassionate care and understanding to patients and their families. In short, caring for and about patients with cancer is what I do—it also is who I am.

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