

Both Sides Now

Many of us working in the specialty of oncology experience confounded shock and disbelief when we or one of our family members are diagnosed with cancer. In some way, we subconsciously feel that if we dedicate ourselves to helping those fighting the disease, then maybe we gain immunity. As many of us have learned, this is not the case. I first experienced the shock and disbelief of a cancer diagnosis two months before graduating as a clinical nurse specialist in oncology. I was diagnosed with melanoma at a time when I was trying to finish my thesis and embark on a new advanced practice role. At that time, my vulnerability was focused on the impact of my diagnosis on my profession. How could I take care of patients with cancer and be a patient with cancer myself? I was young and confident that I would beat the disease, but I was afraid about when I could start a family without risking disease recurrence. The spiritual bargaining that takes place when we are diagnosed with cancer is certainly dependent on the developmental stage in which we find ourselves when diagnosed.

My husband was diagnosed with melanoma 10 years ago—approximately 15 years after I was. He was in his early 40s, so his fears were different than mine when I was diagnosed. He worried about living long enough to see his only child, a fourth-grader at the time, graduate from high school. Feeling powerless, he embarked on a stereotypical male midlife crisis. The Porsche was fun for me, too, but I had different fears than my husband. As an oncology nurse, I was acutely aware that his lymph node involvement meant a more precarious stage of disease to watch and worry. When we left the hospital after his surgery—it was Daffodil Day—a nurse handed me a bunch of blooming daffodils, instead of the other way around. Once again, I was feeling the shock of transitioning from my professional world into the world of the patient (Bush, 1999). Four years after my husband's diagnosis, my younger sister was diagnosed with premenopausal breast cancer. I traveled

the journey beside her through mastectomy, chemotherapy, and reconstruction. During these personal crises, I gained greater insight into the cancer journey that my patients and families confronted. I became more dedicated to my profession, convinced that I could apply my own life lessons to become a more therapeutic oncology nurse.

Most recently, during a family reunion, I was admitted to the hospital for what was

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believed to be a routine appendectomy. Instead, an unexpected 5 cm tumor of unknown origin was found clinging to my appendix. I knew all too well that a tumor of that size, of unknown origin, meant dysplastic, dedifferentiated, and, frankly, scary cells. Shock and disbelief took the form of numb awareness and despair. To my benefit, my oncology colleagues started doing everything they could to get me the best medical attention as quickly as possible. As numerous pathologists were trying to decipher my slides, I began a five-day ordeal of physical examinations, scans, and biopsies. Every hour of every day became an emotional roller coaster. What lit up on the lower right quadrant on my scan? Was it the recent surgery or the right ovary? What lit up in my right breast? A mammogram nine months earlier had been negative. I felt dizzy and almost fainted when the oncologist told me that a breast malignancy had been found and needed to be confirmed by biopsy. But that still did not explain the appendiceal tumor. Four surgeries—a right colectomy, abdominal hysterectomy and oophorectomy,

two lumpectomies, and sentinel lymph node biopsy—later, I was diagnosed with stage II ovarian cancer and stage I breast cancer. The physical and emotional challenges had just begun. As Nail (2001) eloquently expressed, I began “coping as fast as I could.”

Here I was again, on both sides—a professional oncology nurse and a patient with cancer. How could this be happening to me? Ironically, 11 months prior, I had started a nurse practitioner position in a private practice working predominantly with patients with breast and ovarian cancer. Now I was facing similar emotions, similar fears, and the same treatment(s) as the many women I had cared for. I had been holding their hands with empathy and encouragement, but now I was questioning myself. Could I be as courageous as my patients? Could I travel a similar journey with their dignity and strength? In my work, I was equipped to provide advice and comfort for my patients, but suddenly, I felt ill equipped to advise or comfort myself.

At times, the anxiety was overwhelming and immobilizing. It was early-stage disease, but I had two separate malignancies and my third lifetime diagnosis. Internal fears and questions were endless. My sister and I both tested negative for the *BRCA* gene mutations, but what about those genes yet undiscovered? Was it my lifestyle? Was it my stress level? Intellectually I knew that feelings of guilt and worry were of no value, but on an emotional level, those feelings were real and painful.

It did not take me long to realize that I was feeling powerless; in that fragmented state, I had difficulty falling back on my education or oncology experience. At times, my experience seemed emotionally much harder *because* I was an oncology nurse. I knew too much about the disease I was confronting and the treatments that lay ahead, and I feared

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that my professional caregivers would assume that I clearly understood what to expect and how to care for myself. My fear proved to be true in numerous cases. One radiologist brought me into his office to show me my mammogram, at the same time declaring that the density of my breast tissue made the suspicious lesion very hard to biopsy. I felt faint and speechless. After my second major surgery, I could not get adequate pain relief from my patient-controlled anesthesia pump. The nurses caring for me had difficulty understanding my questions regarding how to reset the pump. Breakthrough pain relief was not offered, and I did not think to ask for medication I knew should have been prescribed. I spent my first postoperative night in severe pain until an advanced practice nurse colleague visited me early the next morning and immediately became my advocate to get me the relief I needed.

A two-part qualitative study (DeMarco, Picard, & Agretelis, 2004; Picard, Agretelis, & DeMarco, 2004) addressed similar personal and professional vulnerabilities felt by nurses who suddenly found themselves living in two worlds—that of the patient and the professional caregiver. Many of the nurse subjects interviewed experienced similar fears and vulnerabilities. One of the research questions investigated was, “Is being a nurse an asset or liability when diagnosed with cancer?” As I learned, it is both. Being a nurse can be an asset when one needs to access clinical resources and expertise in an expedient manner. My oncology colleagues became my greatest support. As the study subjects described, my professional knowledge increased my understanding of my diseases and treatments, but that knowledge also added to my fears. I worried that caregivers would assume that I knew exactly what to expect and how to handle the outcomes. In contrast, the transition from caregiver to care recipient from colleagues and family members was difficult.

Similar to the findings of the two studies, I have felt a need for continued support throughout my treatments and beyond. When I was initially diagnosed, the flowers, cards, and gifts felt like an earthly eulogy being sent to me before my time. Support during chemo-

therapy treatments was invaluable. I quickly learned which colleagues, family members, and friends I could depend on for compassion and support. I began to call these guardian angels my “tear catchers,” and I trusted them to advise and guide me.

From my 19-year-old son shaving my head after the first clumps of hair fell to my sister practically moving into my family room, I embraced the silver linings that the cancer journey brings. I gained a greater understanding regarding the challenges of symptom management. On a continuum from scalp pain to peripheral neuropathy, at times, everything hurt. “Bone tired” fatigue became the most distressing symptom negatively affecting quality of life. I was prepared emotionally for alopecia but unprepared for the discomfort of wigs and scarves. The realization that this body-image change would continue for close to a year of my life has been difficult. I mention one body-image change that steals the sense of self, but there are many (e.g., losing total body hair makes you feel stripped bare even with clothes on). Comical worrying also surfaces. For example, what if I embraced someone too tightly and stood back only to find my wig or eyebrows sitting on his or her shoulder?

Support wanes as treatment drags on. Radiation therapy often seems benign, even to healthcare providers, compared to chemotherapy. But as I have learned, it certainly is not. One of my dear colleagues, a breast cancer survivor, described crying during her simulation. She worried during all the bustling activity that the therapists did not really know what they were doing. The many radiation props used for positioning, the body tattooing, and the constant exchange of unknown numbers between the therapists are anxiety provoking. Another close friend and survivor described feeling like she was being crucified with her arms held out and her chest bare to the world. I now understand why a former patient of mine described radiation as “creepy” and said that if the tissue being irradiated becomes reddened, raw, and painful, it feels like you are being cooked past done.

How can the oncology nurse integrate these life experiences into her or his work? Nurse cancer survivors reshape their clini-

cal practice by deepening their level of compassion (Picard et al., 2004). Through my personal confrontations with cancer for myself, family members, and friends, I have learned this to be true. I have truly walked the path of my patients. I am more dedicated to my chosen profession, and my personal experiences with cancer have not broken my spirit. I feel more knowledgeable and confident to be an advocate and caregiver for my patients. I have so much more to share with my colleagues, and I will need their continued support as I transition back from the patient world to my professional role. According to the nurse cancer survivors in Picard et al.’s study, role ambiguity and disclosure are so very challenging—I may find that to be true. I have been on both sides now. My heart is pieced together with silver linings. I have hope that I am a stronger and more empathic human being and oncology nurse. Martocchio (1985) said, “Hoping is coping” (p. 297). In that context, I think I am coping well.

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