MAKING THE MOST OF BREAST CANCER

The narrative chronicles my reactions as a health care consumer receiving treatment for breast cancer and how self disclosure of those experiences has positively impacted classroom teaching.

By Yvette Murray

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With the beginning of the fall semester only days away, one of the essential items on my "to do" list is a trip to Jodie's Coiffures. As Jodie cuts my hair, she remarks that it is very thick and needs thinning. She jokes about how this time, two years ago, she felt guilty about charging me for a haircut because I had so little hair. Jodie intends to be complimentary, but her comments produce an all too familiar knot in the pit of my stomach that happens when I recall the most frightening experience of my life.

There was no warning that anything was amiss. I felt very healthy and energetic, as I waited my turn for a mammogram. The weather was warm and sunny, and I resented having to spend time in the clinic on such a beautiful winter day. It was also one week before classes were to begin, and there was still much work left to be accomplished. Since no one in my family had ever had breast cancer, the examination seemed to be an inconvenience simply to please my gynecologist. After completing the procedure, I left the clinic feeling confident that the matter was resolved for another two years.

Three days later, the clinic called and asked me to return for more x-rays, stating that the previous ones were unclear. That explanation sounded peculiar because the technician had checked the film before I had been allowed to leave the clinic.

Since there was no point to hassling the receptionist, I made another appointment. This clinic visit was very different; the procedure was painful and many more x-rays were taken. By this time, I was suspicious and asked to speak to the radiologist. I was told that he was very busy. When it became apparent that I was not leaving without an explanation, the radiologist appeared. He perfunctorily informed me that I had a lesion in my left breast and would need a biopsy.

The news that I needed a biopsy was unsettling, but I was still not unduly concerned because I thought that only women with a familial history of breast cancer were seriously at risk. My assumption was that I probably just had a cyst, or that the lump was scar tissue from a softball injury. With the semester beginning, I wanted to get the problem promptly dispatched. Both my primary care physician and gynecologist recommended the same surgeon.

I was pleasantly surprised that the surgeon was a woman. Her office staff was very friendly and helpful in arranging an appointment that did not interfere with my teaching schedule.

Several days before my appointment, I went by the radiology clinic to pick up the
mammogram films for the surgeon to review. They handed me the x-rays in a large unsealed envelope. Before driving away from the clinic, I sat in the parking lot and opened the envelope. The words in the radiologist’s report leaped off the page - a two centimeter lesion having the characteristics of carcinoma! At that time, my world turned upside down, because to me, breast cancer equaled death. I was familiar with the grim statistics that over 46,000 women die annually in the U.S. from breast cancer. My fatalistic outlook was also colored by the propensity of the news media to hype sensationalistic accounts of deaths from this insidious disease. Success stories about women surviving breast cancer are far less prevalent.

The ensuing days before the biopsy were filled with suffocating fear. None of the relaxation techniques that I used as a social work practitioner were effective. I could not eat, sleep, or concentrate because a red neon sign kept flashing cancer, cancer, cancer in my mind. The opportunity to verbalize my terror would have lessened its impact; however, I could not unburden myself to friends or colleagues because my illness had triggered their own mortality issues. To retain my sanity, I continued to teach until the day of the biopsy. When the pathology report confirmed breast cancer, it was not a surprise since neither my personal physician nor the surgeon had held out any false hope.

The days following the biopsy had a sense of unreality about them. How could I possibly have breast cancer? There was no palpable lump, no overt symptoms! I felt as if I were sleepwalking through a dream from which I would eventually awake. As I planned with colleagues to cover my classes and made decisions about the type of surgery to undergo, it was as if someone else were doing these things. When the day for surgery arrived, there was some relief in that I was taking steps to resolve the problem. This sense of relief was short-lived, when the morphine haze wore off, and I became fully cognizant of the extent of the five-hour operation. In addition to a modified radical mastectomy, I had chosen to have reconstructive surgery at the same time to avoid two separate surgeries with general anesthesia. Mistrustful of implants, I had opted for a procedure in which abdominal muscle and tissue is used to reconstruct a breast. As a result, I was dealing with both the mastectomy and major abdominal surgery. It was excruciating to cough or sneeze, and getting out of bed required four-letter words and considerable loss of tooth enamel. I tried to rationalize that the misery was worth the price to get rid of the cancer, but then came more bad news, the cancer had spread to one of the lymph nodes. When the oncologist explained the details of the post-operative pathology report, he mentioned that my chances of being cured would improve if I took chemotherapy and Tamoxifen. That was the first time anybody had mentioned that there was a possibility I could be cured! That ray of hope enabled me to endure the miserable treatments that were to follow. On many occasions in social work practice classes, I had spoken of the need to instill hope in clients. The importance of this message, previously delivered on an abstract level, came home to me in a very personal, intimate way.

When I was able to leave the hospital, I found out firsthand the true meaning of a support network. My freezer had been stocked with casseroles for lunch, and every night, a friend brought over a hot meal. After days of nausea in the hospital, the home cooking really helped me recover some strength. Friends took turns taking me to doctors’ appointments, picking up prescriptions, and keeping my furry housemates in cat chow and kitty litter. My social work buddies all pitched in to cover my classes and advising responsibilities. They continually reassured me not to worry about the students, and reminded me that my job was to get well. Even though students were not given my unlisted telephone number, some resourceful individuals still managed to call me, while others sent cards and flowers. Being on the receiving end of caretaking for the first time in my professional life taught me valuable lessons about the practical necessities of support systems. Additionally, the tremendous validation of my personal worth,
which I received from such a wonderful support network of caring friends, colleagues, and students, gave me a heightened sense of purpose about teaching, and the courage to use my experience as a health care consumer when I returned to the classroom.

In the weeks following surgery, I was faced with decisions about adjuvant treatment. At issue was whether to take six months of wretched chemotherapy, or simply take Tamoxifen, whose main side effects are hot flashes. While agonizing over the decision, I consulted with my surgeon and two oncologists; however, they were not proactive in supplying information. If I knew the right questions, I received explanations. Nothing in my previous life experience had prepared me for this situation; consequently, I did not always know what questions to ask. Facing decisions with such serious implications without adequate knowledge only exacerbated the profound sense of helplessness that I felt in dealing with a life threatening illness.

With the tantalizing hope offered by my oncologist that chemotherapy would improve my chances of being cured, I agreed to undergo this ordeal. In retrospect, “ordeal” seems too lenient a description; chemotherapy is barbaric! In the clinic where I received the treatments, patients had little choice but to line up in rows of chairs spaced no more than two feet apart, with as many as a dozen people receiving intravenous drips simultaneously. It was terrifying to see other emaciated patients who could barely walk and wonder if they depicted my future. Probably, it was also depressing to them as well to see me in comparatively good health.

The seating arrangement in the chemotherapy room also precluded any privacy. With the chairs so close together, I heard all about other patients’ bad veins, low blood counts, and miserable side effects. Perhaps, I am being too polite by referring to this deplorable situation as simply a lack of privacy. It was inhumane! Under guise of “we are trying to save your life,” there was little respect for the dignity of the patients. When repeated injections of corrosive drugs made the veins in my hand and arm unusable, I had to have a catheter surgically implanted in my chest. This catheter was exposed while I received the intravenous treatment, which meant sitting with my blouse open for the hour it took to complete the drip — in full view of other patients and their family members, both male and female. When I confronted my oncologist, a senior partner in the clinic, about this communal misery, he replied that the staff had taken a poll which indicated that it was good for the patients to be together for treatment. Good for nurses, maybe, because they could easily monitor everyone, but I surely did not see any camaraderie among the sufferers. Obviously, allowing patients some modicum of modesty was not an important consideration to the medical staff.

Another problem with the chemotherapy was that despite repeated queries, my oncologist never fully disclosed the side effects and efficacy of this treatment/torture. I knew there would be hair loss and nausea, but I was not prepared for the extreme fatigue, painful mouth ulcers, and persistent bone and muscle aches. Had I known that these side effects were likely, and would become progressively worse during treatment, I would not have tried to resume a full work schedule. Only sheer stubbornness enabled me to finish the semester. As the side effects worsened, I consoled myself with the notion that the chemotherapy was working, only to find out that there is no scientific way of evaluating its effectiveness in destroying latent cancer cells. My oncologist belatedly admitted that the chemotherapy is assumed to work if the cancer does not reoccur!

And then there were other unpleasant surprises. After a couple of months of chemotherapy, laboratory tests indicated abnormal blood sugar, cholesterol, and liver function. With my confidence already badly shaken by cancer, these findings only increased my terror, especially, when the oncologist was evasive in answering questions. Later, after I was physically able to do some library research, I eventually learned that chemotherapy attacks all body systems, which, in time, generally return to normal. A considerate explanation at the time would have alleviated this needless source of anxiety.

The journey back to wellness has taken one year for physical recovery and an addi-
tional year for some semblance of psychological health. While I no longer wake up thinking of breast cancer, news stories and quarterly checkups still bring back the fear. Unfortunately, there is no closure with breast cancer. Unlike other forms of cancer where five-year disease free survival is considered a cure, breast cancer may return many years later. In dealing with this dilemma, there is a choice to be made — I can be a victim or a survivor. The former implies accepting powerlessness which is alien to my nature. In the psychological struggle to be a survivor, the challenge is to live provocatively, as opposed to living reactively with the knowledge that if the cancer reoccurs, I will likely die from it. For me, the key to winning this psychic struggle has been to find value in the experience of having breast cancer.

The past two years have been a period of reflection and growth which have directly affected me as a social work educator. Facing a life-threatening illness provides the focus to sort out what is genuinely important in life, and I discovered how much I truly love teaching. I also realized that the difficulties which I had encountered as a cancer patient provided valuable insight which would be useful in preparing students to be social work practitioners.

Before I could translate my experiences as a health care consumer into classroom learning opportunities for students, I had to first overcome feelings of embarrassment at having had breast cancer. Intellectually, I knew that there were no rational reasons for these feelings, but emotionally, I understood why women have kept breast cancer a secret. For me to overcome the mental stigma, I had to come out of the closet. Early attempts at disclosure involved speaking at Herstory, a lecture series on topics of interest to female faculty. Initially, I almost choked when uttering the words breast cancer in public, but the response from the audience was very warm and encouraging. Afterwards, several faculty members privately shared their own personal experiences with breast cancer.

Buoyed by the positive audience response at Herstory, the next step was disclosure in the classroom. How much should I tell the students? Would disclosure facilitate learning or be a distraction? As I agonized over these questions, an inner voice kept whispering - do you really want to be known as the professor who has had breast cancer? In resolving these concerns, I tried an incremental approach. The first course in which I summoned enough courage to share some of my experiences involved social work with the aging. At the juncture in the course when the focus was on death and dying issues, I mentioned that I had faced a life-threatening illness. I explained how important it was to me at that time to be able to discuss with an empathic person, my apprehension about the process of dying. I also shared my fears about being in a debilitated state without an advocate to see that my living will was respected. At first, the class was unusually quiet, but eventually several students related emotionally moving experiences concerning the deaths of elderly family members. Since death is usually discussed in abstract terms as something that happens to other people, I also decided to personify the issue by having the students write their own will. Class feedback on course evaluations was quite positive. Students commented that the class discussions on death/dying issues and the assignment to write their own will had made them more comfortable with the idea of working with clients who are nearing the end of their life.

In the aging class, I skirted the nature of my health problems by simply referring to a life-threatening illness. The following semester, I fully emerged from the closet and named the villain in two advanced practice courses and an elective class on health care. By disclosing my reactions to the diagnosis of breast cancer, students seemed to grasp a better understanding of crisis intervention techniques, and the psychosocial connection between mental and physical well being. One student remarked that discussing intervention theories had not been boring!

Thus far, it appears that my concerns about self disclosure in the classroom were unfounded. Rapport with students has never been better. By confiding in the students, a learning environment is created in the classroom whereby students are more willing to take risks and confront their own personal issues. Student feedback indicates that by relating my experiences with breast cancer, I have become a real person to them as well as a teacher. Perhaps, that it is what modeling genuine behavior is all about.
Although dealing with breast cancer has been frightening, it is consoling to find that this ordeal has positively impacted my abilities as a teacher. When I discuss social work values about respecting the dignity of clients and their right to self determination, I can awaken students to the importance of these values by relating my own experiences as a patient. There is also passion in my voice now when I mention advocacy in class, which communicates to students the realization that as social workers, they may be the client’s only resource in an indifferent service delivery system. Since self-disclosure has been so effective as a teaching tool for me, I have encouraged other social work educators to consider sharing their own life experiences with students — in doing so, communication in the classroom becomes truly empathic, and ethical concepts move from the abstract to real life.

In making the most of breast cancer, where do I go from here? In a recent conversation with one of my doctors, he pointed out that while I have been primarily focusing on social workers, it is the medical establishment that really needs to hear from me. I have taken his advice and volunteered to be a presenter on women’s health issues at conferences which target all types of health care professionals. And just maybe, if I am persuasive enough, some patients will receive a little more kindness and respect, and perhaps be treated as an active partner in their own health care. ⧫
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