My Sister, My Patient, and My Teacher

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am one of five sisters, my mother is living, and I have a sister-in-law who I have known since high school. Together, we total seven women. As an oncology nurse, I knew the odds were stacked against us when it came to breast cancer. Today, one in eight women will develop invasive breast cancer (American Cancer Society, 2014). This knowledge did not prepare me for the phone call from my mother informing me that my sister had a palpable lump in her breast. Naturally, I bombarded my mother with a million rapid-fire questions, most of which she could not answer. The first was, "Did she go to the doctor?" "No," my mother replied, "she did not, because she has no insurance." She had been laid off from her job and lost her benefits. My next question was, "Mom, she knows what I do . . . why didn't she call me?" Well, of course, my mother could not answer that. How many times have we seen women present with sizeable tumors or symptoms that they have been aware of for months?

My family scrambled for a clinic appointment. My sister qualified for the NJ CEED (Cancer Education and Early Detection) program, which provides education and cancer screening for uninsured and underinsured persons in New Jersey who meet certain criterion. Diagnostics confirmed what we already knew. Age 40 at the time of diagnosis, my sister's tumor measured 5 x 4 cm with classic inverted nipple and peau d'orange skin. The pathology revealed ductal carcinoma in situ, estrogen and progesterone positive and HER2/neu negative. Physically bruised from the biopsy, mentally numb from the process, and reeling from the diagnosis, my sister was just going through the motions of the almost daily appointments. Looking at my sister, it occurred to me, "How can we ask women to make



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rational, informed decisions about their treatment when they are still absorbing the fact that they have breast cancer?" My sister would have done whatever I said, and I felt the weight of her trust profoundly. She would be treated at the facility and cared for where I worked at the time and by the medical oncologist with whom I worked. I would have done whatever he recommended; I wonder if he ever felt the weight of my trust?

The plan was neoadjuvant chemotherapy followed by surgery and, finally, radiation. My sister's disease was locally advanced, but her prognosis was good. In no time at all, she had an implanted port placed, a new bruise to add to the ones not yet faded, and a date for chemotherapy. I tried to prepare her for the expected side effects of the medications she would be receiving. I focused on the myelosupression and management of nausea and vomiting. I mentioned that hair loss was probable with this regimen and did not try to soften what I later came to know was a huge blow to her. All I cared about was how to keep her safe during chemotherapy and that her

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When I realized how upset my sister was about her hair loss, I was baffled. By comparison, temporary hair loss was not

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a threat to my sister's safety as neutropenia and neuropathy were and, therefore, not as important . . . at least not in my opinion. Objectivity kicked in, and I acknowledged my lapse. I imposed my feelings and priorities onto my sister, my patient. Like so many other women (and men), her alopecia was a daily reminder of her cancer. The psychosocial impact of hair loss is an important factor and can cause considerable stress for patients. One of the good things about being part of a big family is that there is plenty of support to go around, so my lack of empathy went unnoticed.

My sister's therapy progressed without incident or major untoward effects. She opted for hats or bandanas over wigs for comfort reasons and wore them well. She is a casual girl. Surgery came and went. She fumbled with the breast prosthesis and, many times, left it in the top drawer as she left the house. It was cumbersome. When radiation was complete, I heaved a sigh and gave thanks that my sister's ordeal was done.

A couple months later, a colleague inquired after my sister and I happily reported that she was doing well as she finished her course of therapy and was now on tamoxifen daily. My colleague reminded me that now is the time when she would need me the most. When patients are in therapy, they are the focus of a lot of attention from friends and family and often report a sense of abandonment once treatment is concluded. I realized that I had waved the checkered flag a little too soon.

My sister is many things to many people; daughter, mother, wife, friend, and, of course, sister. For me, you can add teacher to that list. She is strong and brave and taught me so much about what it means to have a loved one with cancer. Because of her, I am better able to understand and empathize and promote patient-centered care. Because of her, I am committed to the survivor and enhancing the quality of life for the patient with cancer after the acute setting. When my sister and I began our journey, I thought I was doing her a favor, but in reality, she taught me so much more!

Reference

American Cancer Society. (2014). Breast cancer facts and figures 2013-2014. Retrieved from http://www.cancer.org/acs/ groups/content/@research/documents/ document/acspc-042725.pdf