BRCA Genetic Testing: An RN’s Personal Story

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This story begins in early December 2011. I had received a diagnosis of ductal cancer in situ (DCIS), a noninvasive cancer staged at 0 in the ducts of my left breast (National Cancer Institute [NCI], 2009). The breast surgeon from whom I was obtaining a second opinion discussed lumpectomy versus mastectomy and radiation. Toward the end of the visit, the surgeon suggested that I have a laboratory workup for vitamin D levels. Vitamin D has been found in some studies to reduce breast cancer risk, and levels of vitamin D also have been found to be low in women with breast cancer (NCI, 2012b). I was directed to the laboratory area. Suddenly, the surgeon burst in and announced that no BRCA results were on file at my gynecologist’s office. She informed me that if I carried the genetic mutation, “You will need to have a bilateral mastectomy and salpingo-oophorectomy.” The BRCA1 and BRCA2 genes (breast cancer susceptibility 1 and 2) usually shield women from certain cancers; however, if these genes possess mutations, the risk of hereditary breast and/or ovarian cancer is greatly increased (NCI, 2012a). A pamphlet produced by Myriad Genetic Laboratories (2009) states that those women with BRCA mutations have:

• As much as a 50% risk for developing breast cancer by age 50 years.
• As much as an 87% risk of developing breast cancer by age 70 years.
• As much as a 64% risk of developing a second breast cancer.
• As much as a 44% chance of developing ovarian cancer by age 70 years.

I looked at her in horror and bewilderment. I practiced in the field of psychiatric nursing for most of my 40 years and I could not even remember what “salpingo” meant. She suggested performing the BRCA test immediately in her office. I consented, and after the simple blood draw was completed, I stumbled out the door in a daze.

Although I was only a 10-minute drive from my home, I turned right when I should have gone left and vice versa. I was both crying and laughing at my attempts to navigate out of the maze that my familiar trip to work had suddenly become. I recalled the last words the surgeon uttered: “I guess you are living your worst nightmare.” She was referring to the facts of my family medical history. My mother had died of breast and ovarian cancer at age 43, when I was 16, and her mother, the grandmother I never met, had died of cancer at age 37. I also was of Ashkenazi Jewish descent (Central and Eastern European background), a factor that increased my risk of inherited breast and/or ovarian cancer (Myriad Genetic Laboratories, 2009). In spite of these factors, my sister and I had sailed through our 40s and 50s cancer-free. We had professional careers, exercised regularly, consumed healthy diets, and obtained recommended health screenings that included mammograms.

That evening, when I crawled into bed, I attempted to recall how I had mistakenly concluded that I had been tested for the BRCA mutation and the results were negative. I remembered discussing the test with my gynecologist some years before; she agreed that I should be tested. My insurance company denied the claim; one factor was the prohibitive cost of more than $3,400. I appealed that decision and won, but unfortunately my provider discontinued her care of routine gynecologic patients and I was assigned to the nurse practitioner. The nurse...
practitioner either missed the previous progress notes or I had failed to discuss the issue of testing with her and the test was never obtained.

I anxiously awaited the new test results, which I was advised would arrive in 2–4 weeks. As it turned out, my results arrived five weeks later. There were multiple reasons for the delay. The laboratory was closed an extra eight days because of the holiday season, and my insurance company took a week to deliberate my coverage eligibility for the test. The surgeon who ordered the test delayed responding to a question from the laboratory staff for almost two weeks. Lastly, the office personnel of this surgeon had failed to see the note in my chart to forward results to my surgeon of record. I was angered and saddened by this string of “medical incompetencies,” as I labeled them. The sadness was related to the fact that I also am a healthcare provider and take pride in my professional, competent, and conscientious care of patients.

One positive experience of the five-week waiting period was that I had time to deliberate the serious treatment decisions that faced me. Now I had time to self-talk, discuss with professional colleagues, bare my soul and tears to friends and family, pray, and participate in a local breast cancer support group. I also had a wonderful role model in a friend who began her cancer journey with a diagnosis very similar to mine just about a year before. I began to refer to myself as a cancer survivor a few days after I was diagnosed.

My laboratory results revealed that I had tested positive for the BRCA1 sequencing, which was described as a deleterious mutation. I decided to undergo a bilateral mastectomy and salpingooophrectomy, as the first surgeon had suggested, and managed to coordinate two surgeons (a gynecologist and breast surgeon) to operate on the same day. I believe that this decision was the perfect one for me. I had not accomplished all of my own personal and professional life goals, including my desires to witness my sons’ weddings and participate in the joys of grandparenting. The increased risks of more cancers were too compelling for me to ignore, as well as my family history. I did not want my children, although already older than I was when my mother died, to experience this loss early in their lives. I hope that every woman facing BRCA genetic testing receives the support, love, and the necessary space to achieve the satisfactory outcome that I have experienced. There were no cancers in my lymph nodes, right breast, ovaries, and fallopian tubes; however, one area of my left breast was diagnosed with stage I invasive cancer. I received this news from my surgeon on the second day of my hospitalization; this meant that I also would be facing chemotherapy, which I had not anticipated.

The love and attention of friends and colleagues since my diagnosis continues to support and heal me. Most importantly, the bond between my artist sister Phyllis Green and me has strengthened. That bond is revealed by the images that accompany this narrative. Also, early in the writing of my story, my son forwarded a chapter of a book by Reissman Kohler (2008) that described the effectiveness of the use of other media, such as photography and video, rather than words alone in scientific papers. Reproduced here is a sculpture by my sister titled “Boob Tree,” a four-foot crocheted tree trunk topped by a cluster of candy-pink crocheted breasts. She created it in 1975, and it was featured on the poster advertising the Woman as Viewer art exhibition at the Winnipeg Art Gallery. Boob Tree represents my recollections of my own engorged breasts that nourished my two sons and how the experience of breast feeding was a positive one for me. It also evokes the feelings of pride and love I felt toward my baby sister regarding her accomplishment in the art world.

Another artwork by my sister is a wall relief titled “Pie in the Sky.” The central element is an oversized wedge of pie stuffed with more of the pink crocheted breasts as filling. This artwork represents the culmination of the emotions felt and the acceptance of my decision to remove both breasts; that it was acceptable for them to float away to save my life. Pie in the Sky currently hangs in a guest bedroom in my home; glances of it reinforce the positive outcomes of my treatment decisions.

Writing this article has assisted in my own healing and recovery by allowing me to review and revisit the roller coaster of emotions and the decision-making processes that I had experienced. It also has helped me to appreciate the effects that the BRCA genetic testing has had on my life and the lives of my family members and close friends. I hope that this article may help others facing genetic testing decisions.

References

Myriad Genetic Laboratories. (2009). If your family has a history: Put it to the test. Salt Lake City, UT: Author.


