

PERSPECTIVE

Ductal Carcinoma In Situ Stage 0 Breast Cancer When Less May Be Better

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In 2008, I had a routine mammogram that showed an abnormal finding. After a biopsy, I received the diagnosis of ductal carcinoma in situ (DCIS) stage 0 breast cancer.

I was referred to a surgeon who explained my options. He said that if I had to have breast cancer, DCIS stage 0 is the "best and least" I could have. He said that he was going to treat this very aggressively, which meant surgery and irradiation.

There is no history of breast cancer in my family, but I immediately thought about my dad who had died about 30 years earlier at age 59 years, 8 weeks after he was diagnosed with lung cancer. I contemplated my mortality and the prospect of leaving behind my children and grandchildren.

The "cancer" word scared me to death, so I opted for immediate treatment. Breast-conserving surgery was scheduled the following week, along with MammoSite treatments (Hologic Inc), a sequence of 10 internal radiation treatments, 2 a day for 5 days, in which a rod is inserted into the breast, into a balloon that has been placed there for that purpose. After the treatment, I was told that I would need to see the radiologist every 6 months for 5 years.

After the first day of irradiation, I had reservations about continuing. The risk of the radiation seemed too great compared with the condition I was diagnosed with. I had researched DCIS stage 0 breast cancer and learned that at this stage, abnormal cells have not left the milk ducts and invaded the breast tissue.

I asked to meet with the radiologist before the next day's treatments to share my reservations. During that conversation, I was led to believe that if I did not have treatment, the breast would eventually be lost to cancer. I continued treatment.

Two weeks later, after completing radiation treatments, I was scheduled for a follow-up appointment with the surgeon. As I was leaving, the nurse said I should see

an oncologist to determine if any medications were needed. Until this point, I had not seen an oncologist.

The oncologist told me that what I had was not cancer and rarely becomes cancer. After I went home, I called him to confirm that I heard him correctly and asked him to write a letter to me with this information. He kindly did write a letter and I still have it. He did not comment on the appropriateness of the treatment that I had received.

To this day, I worry about the effects of the radiation therapy, which I feel was unnecessary, and whether it will cause future health problems. Also, I do not want to be branded as a "breast cancer patient" for the rest of my life, so I contacted my insurance company and requested to have my insurance record changed, offering to send them the letter from the oncologist. It was not possible to make any changes, they said.

Wisdom and compassion are needed to look at illness and treatment options through the eyes of the patient. I remember lying on the treatment table, scared to death, waiting for the radiation rod to be inserted inside my breast. This was the hardest thing I had to endure in my life, next to losing my twin sister. A prayer blanket handmade by members of my church brought much solace.

Fear should not be used to encourage patients to comply with a treatment plan. A better approach is to provide patients with the evidence of need for treatment, the effectiveness of treatment options, and the benefits and risks of each. Patients can use that information and combine it with their preferences and values to help them decide what is best for them. In retrospect, I have come to believe that all women with DCIS stage 0 of the breast should take time to consider options for treatment (or no treatment), get opinions from a range of experts, and talk with their family, friends, and other patients before making a considered decision about potentially harmful treatment.

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