LISTEN TO THE PATIENT

". . .his patients should be his book, they will never mislead him."

Paracelsus, 1493–1541
Book of Tartaric Diseases

An Unforgettable Surgery

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For more than 50 years, *Cancer* has explored every facet of malignant disease, including morphology, therapy, epidemiology, biology, historical perspective, and basic science. However, the Editors of *Cancer* believe that the human beings who bear the burden of this illness have much to teach us, and we now solicit essays from patients and family members about their experience. ***Cancer* 2004;101:1–2.**

I never anticipated breast cancer. As a physician, I knew the risk factors for breast cancer and thought my risk was low. Dutifully, I had annual mammograms, but in March of 2002 a small mass was found, a 6-mm Grade 2 infiltrating ductal carcinoma that was estrogen receptor positive. Still, I felt fortunate it was diagnosed early and anticipated an uncomplicated course.

Soon after the diagnosis, I contacted a close friend who also had early breast cancer. She said the lumpectomy was relatively easy with quick recovery. "It's the arm surgery that is so tough," she recalled. My friend was diagnosed 5 years ago when axillary lymph node dissection was performed on all patients with breast cancer. My surgery was to be a lumpectomy and sentinel lymph node biopsy. I was certain the sentinel lymph node would be negative and my experience with the arm surgery would be better than hers. Intraoperatively, the sentinel lymph node was negative, but 4 days later I received the dreaded call that a micrometastasis was found. The surgeon recommended axillary lymph node dissection.

Fearing the complications of this surgery, I resisted the recommendation. I read studies comparing sentinel lymph node biopsy with axillary lymph node dissection, and the articles clearly depicted the minimal risks with the former and increased morbidity of the latter. Lymphedema is the complication I most feared. At age 52, I felt more active than at any time in my life, both professionally and in activities outside work. As a pediatrician, I work 8–12 hours a day. When not in the office, I am busy caring for my home and family. In the summer, I enjoy golfing with friends. How could I continue all these activities if I developed lymphedema after surgery? Prolonged activity causes arm fatigue and will increase the complications of this disorder. I did not want to stop doing things I loved because of a heavy, swollen arm.

Based on the pathology of my tumor, it was doubtful that a metastasis would be found in a nonsentinel lymph node. Currently, the ACOSOG Z0011 trial randomizes patients with early breast cancer and a positive sentinel lymph node to undergo axillary lymph node

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dissection or no further axillary surgery. Although my treatment center does not participate in this trial, at another center I could have been considered for the observation-only group.

It was 2 months before I was able to make the difficult decision to go for the axillary lymph node dissection. During the interval after my original surgery, I had minimal discomfort and returned to full activity within a week. I even traveled to Guatemala–a trip planned 8 months before my diagnosis– with a medical team and cared for approximately 150 children. When I returned, my physicians and family strongly urged me to undergo the axillary lymph node dissection. I finally agreed. As I expected, the lymph nodes were all negative.

The most common complications to the arm after an axillary lymph node dissection are pain, numbness, decreased mobility, loss of strength, and, most dreaded, lymphedema. Up to 25% of women develop lymphedema and 75% experience 1 or more of the other long-term sequelae. Another complication, often not discussed, is anxiety–the fear of what might happen to the arm.

For those without lymphedema, there is the worry it could develop at any time. It is most likely to occur within the first 3 years after surgery but has been reported to occur 10–20 years later. Fortunately, most breast cancer treatment centers now provide information to reduce the risk of this problem. To prevent lymphadema after axillary lymph node dissection, a woman should adhere to numerous lifetime restrictions. She should avoid any injury to the arm such as bruises, cuts, burns, sunburns, or sports injuries. Vigorous repetitive movement against resistance is discouraged. She is advised against lifting too much weight with the affected arm. Many women are unaware that lymphedema can develop during air travel due to cabin pressure changes. Sadly, even when all recommendations are followed, some individuals still experience arm swelling.

The fear of lymphedema affects most aspects of my life. For prevention, my treatment center provides conservative recommendations which I follow. To do otherwise is to risk consequences I am not willing to face. In the office, I avoid lifting toddlers and children on my affected arm, which unfortunately is also my dominant arm. Outdoors in the warm weather, I take extra precautions to protect my arm against sunburn or bug bites. And in the winter, my family discourages me from activities I used to enjoy, such as shovelling snow. We all worry about my arm.

Fortunately, to date, I have not developed lymphedema, but like 20% of women, I do have persistent arm pain. For almost a year after my surgery, I took large doses of nonnarcotic analgesics to be able to function at home and work. Although the pain has lessened since the surgery, it is still severe 2–3 days a week. Because I have full range of motion , I do not have shoulder pain. But I do have neuropathic pain in my upper arm and axilla, usually precipitated by increased activity but very unpredictable. Sometimes it burns and tingles; sometimes it is sharp and stabbing. When the pain is present, routine activities are problematic. At my job, it is difficult to restrain a feisty child for an ear examination. At home, chopping vegetables for dinner is taxing. And although I continue to play golf, afterwards, my arm hurts for hours.

Despite my fear of lymphedema and the discomfort in my arm, I am still very active. I learned to adapt to the surgical complications and recommended restrictions, but the pain and limitations are an ongoing reminder of breast cancer. A neurologist friend advised gabapentin, which has helped relieve the neuropathic pain. Over the past 20 months, I found answers to some of my problems, but questions about this surgery remain.

Axillary lymph node dissection usually is performed for staging purposes, yet a large percentage of women with negative lymph nodes die of breast cancer. How accurate is axillary lymph node status at predicting outcome? Several studies conclude that preserving the intercostobrachial nerve during this surgery can decrease pain without increasing complications. Should surgeons give more consideration to preserving this nerve? Finally, and most important, realizing the complications and risks of the surgery, should an axillary lymph node dissection be performed in cases in which there is not clear medical benefit?

Several months after undergoing axillary lymph node dissection, I happened to buy a breast cancer research stamp. The stamp is filled with symbolism. It is a line drawing against a rainbow background that depicts Artemis, Greek goddess of the hunt. I was most interested in her right arm, which is reaching in her quiver for an arrow to do battle. The foe, in the symbolism of the stamp, is breast cancer. Her arm appears to move easily without pain, without limitation. It is my hope that in the near future, arm morbidity due to axillary lymph node dissection can be reduced. Then like Artemis, more breast cancer survivors may use their arm not with fear and discomfort, but with courage and strength.