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ETHICS CASE

The Importance of Quality of Life to Patient Decision Making in Breast Cancer Care

Commentary by Heather Macdonald, MD

When Marsha was diagnosed with stage I breast cancer, her gynecologist referred her to Dr. Martin, a highly respected surgeon, to discuss removal of the mass. Dr. Martin recommended a mastectomy, explaining that he had long-term experience and success with the procedure, with very low complication rates and few cancer recurrences in his patients. Marsha was comforted by Dr. Martin's confidence and success rate, but left the appointment greatly concerned about undergoing such extensive surgery.

After some online research, Marsha found that, for women her age (38) diagnosed with early-stage breast cancers, a lumpectomy was an equally effective tumor-removal alternative to mastectomy. She read that, while the latter may provide more peace of mind by removing the entire breast, it was a more invasive procedure, often followed by reconstructive surgery and a significant recovery period. The lumpectomy would preserve most of the shape and sensation in her breast. And, as an avid runner who raced frequently and had an active lifestyle overall, Marsha considered the shorter recovery time and avoidance of reconstruction added benefits. Of course, her health and curing the cancer were her foremost concern, but, after careful consideration and many conversations with her family, Marsha decided to ask Dr. Martin to perform a lumpectomy instead of a mastectomy.

Marsha was surprised by Dr. Martin's reaction. Although studies had shown no statistically significant difference in survival rates in patients with stage I breast cancer who underwent lumpectomies versus mastectomies, Dr. Martin said that, based on his own training and experience, a mastectomy was a much better way of preventing recurrence. He said he did not want Marsha to have to face the possibility of a second surgery should the postoperative pathology report show positive lymph nodes or unclear margins. Dr. Martin urged Marsha to rethink her decision.

She left his office confused and overwhelmed. While her limited research had led her to believe that a lumpectomy was the better choice for her, she respected Dr. Martin's experienced clinical judgment and his concern for his patients' well-being. "When it comes to breast cancer in a woman your age," he told Marsha, "there is no such thing as being too cautious." Marsha would have to travel to a nearby city to find a surgeon to perform the lumpectomy if Dr. Martin refused. Since both forms of treatment had comparable outcomes, Marsha wondered whether she should put aside her own preferences and follow Dr. Martin's recommendation.

Commentary

The emotional minefield of a cancer diagnosis in a young woman can amplify conflict between a physician's recommendations and patient's wishes. Evidence-based medicine and adherence to ethical principles provide guidance for navigating these difficult situations.

Data on Treatment

First, consider the medical evidence. Women with early breast cancer have excellent survival rates. Studies starting in the early 1970s show equivalent 20-year survival rates for patients with breast cancer treated with mastectomy and those treated with lumpectomy, as long as clear margins are achieved and lumpectomy is followed by radiation therapy [1]. Recurrence rates are higher for patients who undergo lumpectomy (10 to 15 percent recurrence risk after lumpectomy and radiation therapy) versus mastectomy (2 to 5 percent recurrence risk) [1], but with close surveillance those recurrences can be caught and treated before they become life-ending diseases.

Patients who carry mutations in the BRCA genes may have more limited treatment options; their lifetime risk of recurrence in either the affected or unaffected breast is high enough that they benefit from double mastectomy [2]. Another group whose options may be limited comprises younger women, who tend to be diagnosed with later-stage disease because there is less routine screening of this population. More aggressive tumors, those that are hormone-receptor-negative or HER2-positive, more common in young women, lead some experts to recommend more drastic therapies for this group of patients, with the goal of protecting the many decades of life we hope this 38-year-old patient will have.

Further, recent advances in genomic profiling of tumors have increased our ability to understand the inherent indolence or aggressiveness of tumors, allowing oncologists to tailor treatment to the genetic profiles of breast cancers, using chemotherapy more selectively to combat the most threatening cancers while sparing patients with more indolent cancers from undergoing unnecessary and harsh treatments. For Marsha, the patient presented here, incorporating her BRCA mutation status, hormone receptor status (estrogen and progesterone), HER2 status, genomic profiling, and clinical stage, specifically involvement of lymph nodes, would allow a more personalized treatment approach.

Ethical Principles

Patient-physician relationships are guided by several ethical principles: nonmaleficence, beneficence, and respect for patient autonomy. First, physicians are charged with avoiding causing harm. Second, they are obligated to offer their best care to restore patients to health. Third, physicians must treat patients as independent persons capable of governing their own health and health care, presenting them with all the information necessary to make informed decisions. In the past several decades medical care has moved away from a paternalistic "doctor knows best" approach to one based on shared decision making. In this approach, the knowledge and expertise

of the physician is combined with the value system and understanding of the patient to create a consensus approach to treatment decisions.

In the case above, the physician is bringing his years of specialization and experience to offer the patient what he believes will maximize survival and minimize harm. He also has an obligation to present the relevant medical evidence in its entirety, explaining the benefits and risks of both mastectomy and breast conservation.

The patient contributes her values and desires for her therapy. Factors that may influence breast cancer patients' decision making include anxiety regarding disease recurrence, discomfort with mammograms and biopsies, concerns regarding body image and sexuality, length of treatment time and recovery, family experiences with breast cancer and treatment, and others. When faced with a choice of mastectomy or lumpectomy, some patients may have more anxiety about recurrence and therefore reject breast conservation in favor of removal of as much breast tissue as possible to reduce that risk. Another patient with a similar tumor may worry about feeling disfigured by a mastectomy and fear her self-confidence and intimate relationships would suffer, and therefore would prefer treatment that conserved her breast. Since evidence indicates that the two approaches are medically equivalent in terms of survival (although not equivalent with regard to recurrence), it is the patient's articulation of her values and concerns that informs the medical evidence presented by the physician. Together they come to a decision that is both medically sound and in keeping with the life the patient wants to lead. This shared decision making is most possible in an atmosphere of mutual respect in which both parties feel their contributions are heard and acknowledged. If a patient does not believe her wishes are being considered or feels her doctor is not listening to her concerns, she should find a doctor she trusts to communicate more openly with her.

If a physician who finds him- or herself in conflict with a patient, exploration of the patient's values, fears, and goals for treatment may allow the two of them to find common ground and reestablish trust. As she is unlikely to die in the near future of her disease, it is reasonable to discuss more than just cancer survival in her counseling and recommendations. Questions that can be useful to initiate this dialogue include:

- What is your goal in treating this cancer beyond being cancer-free?
- What do you fear about treating your cancer?
- What do you fear most about your disease after your treatment is completed?
- How do you picture your life in 5 years? How do you picture your appearance?
- What do you think you will look like after surgery?

Not every patient will be able to answer these questions immediately, but physicians who help patients articulate their goals and fears will gain critical insight into their values and expectations for therapy. Many patients will simply start with a desire to survive; if reassured they are likely to live at least 5 years, they will consider

recurrence, appearance, sexuality and intimacy, and other concerns that will inform their medical choices.

If a physician finds him- or herself in conflict with a patient who is not making a reasonable decision (refusing any medical intervention for breast cancer in lieu of herbal therapy, for example), the doctor is not obligated to provide therapy he or she believes to be useless or harmful. In other words, the principle of nonmaleficence must not be sacrificed in the name of patient autonomy. That would constitute a breakdown of the therapeutic relationship. If this occurs, the physician should refer the patient elsewhere for medical care.

References

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