

When Informed, All Women Do Not Prefer Breast Conservation

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The article by Collins et al¹ in this issue of *Journal of Clinical Oncology* sheds light on the controversy about increased mastectomy rates in the United States and informs the debate as to whether there should be a quality metric for the rates of mastectomy. The authors clearly demonstrate that when breast conservation surgery (BCS) and mastectomy are both options for local treatment, all women do not prefer BCS. Certainly, when there is considerable variation in the rates of mastectomy by race and geographic region, there is cause for concern as to whether patients are being adequately informed about their choices.^{2,3} Morrow et al demonstrated that, in a review of more than 16,000 patients across the country with stage I and II tumors, mastectomy rates ranged from 46% in the Northeast to 68% in the South.⁴ Although the study by Collins et al represents a relatively uniform population from the Northeast, we know that all of the women in the study were extremely well informed, as demonstrated by their high scores on the knowledge survey, and understood the choice between, and the impact of, mastectomy and BCS. Even though only half of patients enrolled finished all three questionnaires, the authors state that the responders and nonresponders were not significantly different. Armed with full understanding of their choices, a substantial fraction of women (35%) preferred mastectomy.

This report shows that, in this fairly well-educated, predominantly white population, specifically eliciting preferences from women about three issues will help both the patient and the physician to come to a decision about the optimal choice for that patient. For the surgery decision, the questions are how interested are you in preserving your breast; how important is peace of mind; and how important is it for you to avoid radiation?

Peace of mind likely reflects the interest on the part of the patient to forget about that breast and to stop worrying that there is a remnant of disease, which can recur. In discussing these issues with patients, it is not uncommon for women at high risk, who have been screened intensively and have had the experience of multiple recalls and biopsies, to choose bilateral mastectomy when diagnosed with breast cancer. For them, the desire to have peace of mind, to avoid the experience of screening, and to eliminate the anxiety associated with a recall for additional imaging and biopsies makes mastectomy seem the obvious choice.

Choice also depends on life circumstances. For the young married woman with small children versus a woman who has grown children, or for a single woman versus a woman who has already found her life partner, motivation and priorities may be different, and

these will inform decision making and treatment choices. It is interesting that the Dartmouth group showed that younger women and those with higher stage of disease chose mastectomy even when they had the option for BCS. Sometimes women feel less certain that screening will work for them when they have a larger tumor at the time of diagnosis, especially if the cancer was not detected on routine screening. However, some women will have just the opposite reaction and want to do anything they can to preserve the breast. What is important is that there are genuine differences between treatment choices among women with similar presentations. It is because the options are associated with equivalent survival that it is so critical to make sure that women are full participants in the decision-making process.

When initially undecided, and given tools and time for decision making, most patients chose BCS. Interestingly, the slightly higher local recurrence rate associated with BCS was not significant in influencing decisions, possibly because the difference is small and other factors are more dominant. Of the 78 patients who were sure about the decision at the beginning of the process, 20% changed their minds—almost all to BCS from mastectomy. Most changed their minds after realizing that BCS truly was an option. This highlights the importance of giving women time to absorb the information and think about their decision. Many women will feel differently a week after their diagnosis. The initial reaction can certainly be to just get rid of the breast. Once the shock of their cancer diagnosis fades and they have time to reflect on the treatment options and their implications, a significant portion of women will change to BCS. The educational process used by the group described by Collins et al built in time for reflection by making sure women watched the shared decision-making video tape and had time to consider their choices before the surgical consultation.

This study also clearly shows that the information that is elicited from patients about their values can be presented to the surgeons at the time of consultation; this information seems to increase the efficacy of the consultation. In this study, 43% of women were unsure about their surgical decisions at the beginning of the process. Even after seeing the shared decision-making tool, 33% were unsure. When informed patients met with surgeons aware of patients values and preferences, the uncertainty resolved for almost all patients. This suggests that if we provide women with the salient facts, elicit their preferences, and discuss the options in that context, they come to a consultation better informed and more involved in the process. It also underscores the value of the surgeon's role in the decision-making

process and suggests that these decision-making tools are an adjunct, not a substitute, for the physician consultation. For the rare patient who truly wants the surgeon to make the surgical decision for her, the surgeon is more aware of which questions to ask to elicit the information that will help select a choice for the patient that is concordant with her values. It is important that each clinician have a method to ensure a framework for a good, thoughtful decision for each patient. For some practices, the entire set of survey tools could be implemented routinely. For others, they could simply ask their patients the three critical questions. This research approach has been successfully applied to other preference-sensitive decisions^{5,6} and should be extended to other decisions in breast cancer.

Although not the explicit purpose of the article, the data strongly suggest there is a strong value concordance between the concern for breast preservation and the subsequent choice of BCS. A similar concordance exists between the need for peace of mind or desire to avoid radiation and the choice for mastectomy. This demonstrates that we can use surveys to elicit the relevant personal values from our patients to help them with their decision making. For example, if a patient strongly prefers to avoid radiation and understands what this intervention entails, additional options may be available for the patient. Preservation of the breast and avoidance of radiation are not always mutually exclusive propositions. For small, hormonally sensitive, invasive cancers in women older than 70 years, endocrine therapy alone (without radiation) is associated with low local recurrence risk and equivalent survival to radiation plus endocrine therapy. There are data that suggest the same outcomes for women age 55 to 70 years.^{7,8} This is particularly important in rural areas, where one factor that drives the mastectomy rate is the lack of proximity to radiation centers.^{9,10} If we are able to avoid radiation in some older women, we may be able to counsel them that BCS is still an option.

Recent trends demonstrate that there is an increase in mastectomy rates and even bilateral mastectomy rates. This has caused some alarm in the lay press.¹¹ A recent report¹² from the Mayo Clinic has demonstrated a recent increase in both magnetic resonance imaging (MRI) rates and mastectomy rates. In their review of 5,463 patients from 1997 to 2006, the overall mastectomy rate decreased slowly from 45% in 1997 to 30% in 2003, but was back up to 43% in 2006. The rate of mastectomy was higher in the subset that had undergone MRI (52% v 38%). Although MRI may be a factor in raising the specter of additional foci of disease, it would seem from the Dartmouth group that there is a genuine choice by many women for mastectomy, and that the choice is dominated by the desire to either preserve the breast or to remove all the breast tissue and move on. The increase in MRI use alone does not explain the increase in mastectomy rates, but may be a contributing factor. Given that MRI often finds additional lesions, patients may choose to have a mastectomy in lieu of additional multiple MRI-guided biopsies. Given the high false-positive rate associated with MRI, patients should be counseled not to make a decision about mastectomy without a tissue diagnosis of cancer in multiple sites. It is possible that MRI may highlight uncertainty about residual tissue and contribute to the choice for mastectomy to provide desired peace of mind. The Dartmouth group does not report the rates of MRI in their cohort, nor whether that was a factor in the patients' decisions.

Another factor that may be affecting mastectomy rates is the option for greater access to reconstruction. Improvements in reconstruction certainly make mastectomy a more palatable choice for many women. Interestingly, 60% of women who chose mastectomy in

this study did not elect reconstruction; however, that may not be representative of all ethnic groups and geographic areas. As reconstruction options continue to improve, new techniques such as total skin-sparing mastectomy may result in even higher rates of choice for mastectomy in the future.^{13,14}

What is particularly unique about the Collins et al¹ study is the clearly described process for education and promotion of informed decision making. Feedback to clinicians regarding the patient's level of understanding and personal values is critical. Figure 3 of the article by Collins et al shows that when true shared decision making is used, decisional conflict plummets (ie, the informed patient has a discussion with a physician knowledgeable not only about the subject matter, but also the patient's values). At the University of California, San Francisco, we have developed some unique tools to elicit patient's concerns and values (Consultation Planning and Recording),^{15,16} which we have also shown reduce decisional conflict. What the clinician should take away from these studies is that there is great benefit to providing educational materials before consultation; that measuring patient knowledge can help expose gaps in patient understanding of the options; and that there are key questions the physician can ask to help ensure that the patient is making a decision concordant with her values.

The major drawback of the study by Collins et al¹ is that it is a single-institution study and reflects the values of white women from New Hampshire. We suggest that this decision process be more broadly disseminated, implemented, and studied using the tools described in the study to help us learn if there are differences across ethnic and racial groups. Such studies include decision aids, knowledge/value concordance surveys before the surgical consultation, sharing of the surveys with the clinician, and measuring of decisional conflict. A significant effort will be needed to translate these tools into other languages and validate them, but the information derived from this work would be invaluable. The study by Collins et al lays an important foundation on which we should build.

There is one final take-home message from this elegant study: Without a doubt, it is critical not to make rates of BCS a quality measure. Patient knowledge and understanding of their surgical options and value concordance are all more appropriate choices, although harder to measure. We know that knowledge can be assessed and preferences elicited. Surely the goal is a good decision. The key to offering a choice is respecting the choices patients make. Some people will choose one path, others a different one. We need to accept that women will have different values and want different choices. Our job should be to make sure patients have the choices, the information, the time, and environment in which to make an informed, value-driven decision.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

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