Do Patients and Providers Agree About the Most Important Facts and Goals for Breast Reconstruction Decisions?

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Abstract: Decisions about breast reconstruction after mastectomy are some of the most difficult decisions a breast cancer patient makes. To make a good decision, the patient should have adequate knowledge of specific facts related to the decision, and the treatment chosen should be consistent with the patient's personal preferences or goals. We sought to identify the most important facts and goals for decisions about breast reconstruction after mastectomy, and to compare patients' and providers' perspectives.

We conducted a cross-sectional survey of breast cancer survivors and providers. Participants rated and ranked the importance of facts and goals/concerns related to breast reconstruction after mastectomy. We compared patients' and providers' rankings using χ^2 tests and compared ratings using *t*-tests.

About 21 patients and 20 providers participated. Facts: Providers were more concerned about the impact of radiation on the success of the reconstruction than patients (60% vs. 24%, 95% CI of the difference: −64, −8). Thirty percent of providers placed the fact that women who do not have reconstruction are equally satisfied as women who have reconstruction in the top 3, whereas almost no patients did (30% vs. 5%, 95% CI: −47, −3). For all 3 of the facts about immediate versus delayed reconstruction, women placed a higher priority on these facts than providers did. Goals: Patients placed greater importance on avoiding use of a prosthesis (33% vs. 0%, 95% CI of the difference: 13, 54). There was a trend toward less patient concern about "looking natural without clothes" compared to providers (24% vs. 40%, 95% CI of the difference: −12, 44).

Significant variability exists among patients and between patients and providers, with respect to the most important facts and goals to guide decision making about reconstruction. Providers should ensure that women understand that reconstruction can be performed immediately or delayed, as well as the likelihood and type of complications. Surgeons should ask each woman which goals and concerns are most important to her. Specifically, they should inquire as to how women feel about using a prosthesis, and how they feel about their appearance with and without clothes.

Key Words: breast reconstruction, breast surgery, breast cancer treatment, decision making, preferences, patient provider communication, decision aid, cancer reconstruction

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Decisions about whether or not to have breast reconstruction after mastectomy and about which type of reconstruction to undergo are some of the most difficult decisions a breast cancer patient makes. These decisions fall into a category of decisions that are called "preference-sensitive." Preference-sensitive decisions are defined as decisions for which the right choice depends primarily upon the patients' personal preferences, and less upon medical characteristics, either because the treatment in question is so personal in nature, or because there is minimal or conflicting data to help patients decide.

For preference-sensitive decisions, the quality of the decision depends on 2 conditions. The patient should have adequate "knowledge" of specific facts related to the decision, and the treatment chosen should be consistent with the patient's personal "preferences or goals."[1] Although some studies have measured breast cancer patients' knowledge about reconstruction,[2,3] and several have assessed patients satisfaction, few have asked patients what were their most important goals and concerns related to reconstruction. We sought to identify the most important facts and goals for decisions about breast reconstruction after mastectomy, and to compare patients' and providers' perspectives.

METHODS

Setting and Design

We conducted a cross-sectional survey of breast cancer survivors and providers. The study was part of a larger study of patients' and providers' perspectives on reconstruction, surgery (lumpectomy vs. mastectomy), and systemic therapy (chemotherapy and hormone therapy). The purpose of the larger study is to develop a set of facts and goals relevant to 3 breast cancer treatment decisions, to be used in survey instruments that measure the quality of decision making about those treatments.[4]

Population

For each decision, a convenience sample of breast cancer providers, including breast cancer nurses, medical oncologists, surgical oncologists, general surgeons, and plastic surgeons, was identified. Providers were identified through colleagues and through provider websites. Eligible providers were mailed the survey and a $10 incentive. Nonresponders were sent a reminder and then another copy of the survey after 4 weeks. Responders received an additional $40 for completing the survey.

A convenience sample of patients was recruited through a combination of newspaper advertisements, flyers, registries, providers, and patient support groups in the areas around Dartmouth Hitchcock Medical Center and the University of Massachusetts Boston. Those who were older than 21, with a history of early stage breast cancer diagnosed within 5 years prior to contact and treated with mastectomy, and who could speak and read English were eligible. Each eligible patient was mailed the survey. Nonresponders were sent a reminder and then a second copy of the survey again after 4 weeks. Responders were given $10 to $25 for completing the survey.

Data Collection

Participants answered questions about facts and goals/concerns related to breast reconstruction after mastectomy. The candidate facts and goals had been generated by patients, medical experts, and decision making experts, and were based on reviews of the clinical evidence and qualitative studies of breast cancer decision making and experiences of breast cancer care.[4] The facts covered the following areas: disease, choices, benefits of the choices, harms of the choices, and the decision situation. The facts are listed in Table 1. The goals and concerns included good and bad health outcomes and other factors that patients reported were critical to their decisions, phrased in their language. They covered the following areas: benefits, harms, other attitudes about nonhealth states, holistic attitudes toward treatment or approach to treatment, and influence of others. The goals and concerns are listed in Table 1.

Participants rated the importance of each fact and goal on a 4-point scale (1 = Not Important, 2 = Somewhat Important, 3 = Very Important, and 4 = Extremely Important). They also selected their top 3 most important facts and goals and could add any additional facts and goals and concerns that they thought were important to decisions about reconstruction.

Analysis

For each candidate fact and goal, we determined the percentage of patients who placed the item in their top 3, and compared it to the percentage of providers who placed the item in their top 3. The asymptotic 95% confidence interval (CI) around the difference between the patient and provider percentages was calculated for each item. Confidence intervals excluding 0 were considered evidence of statistically significant differences in importance ratings between patients and providers. Based on these results, we identified the 3 most commonly selected facts and goals among patients and among providers to see how much overlap there was in the top 3 ranked items. We also examined the patients' ratings of each item on a 4-point scale (1 = Not Important, 2 = Somewhat Important, 3 = Very Important, and 4 = Extremely Important) and compared the ratings to providers' ratings of the same item. We compared the ratings using *t*-tests. A $P < 0.05$ was considered statistically significant.

TABLE 1. Facts and Goals About Breast Reconstruction After Mastectomy, for Rating and Ranking by Participants

Reconstruction fact*
Radiation can increase complications and affect cosmetic result of reconstruction.
About one-third will have a major complication in the 2 yr after reconstruction.
Reconstruction often requires multiple procedures over multiple visits to complete.
Reconstruction can be at the time of mastectomy or delayed for months or years.
Women who do not have reconstruction generally as satisfied as women who do.
Women who have flap are more satisfied with the look and feel than women who have implant.
Immediate reconstruction offers more natural look and feel than delayed.
Implants require less extensive surgery than flaps.
Women who delay reconstruction are as satisfied as women who have immediate.
Prosthesis can provide a "natural look" in clothes.
The data available to provide estimates of complications for reconstruction is limited.
Reconstruction goal*
Look natural in clothes.
Minimize the number of surgeries.
Minimize recovery time.
Look natural without clothes.
Avoid a lengthy process.
Use your own tissue to create a breast.
Do what your doctor(s) think is best.
Do what your spouse thinks is best.
Avoid using a prosthesis.

*Shortened from the original wording.

RESULTS

Response Rates and Sample

The patient response rate was 79%, and the provider response rate was 77% in the larger study. Tables 2 and 3 describe the demographics of the reconstruction patient (N = 21) and provider samples (N = 20).

Ranking and Rating of Facts

Only one reconstruction fact, "about ⅓ of patients who have reconstruction will have a majorcomplication," was most frequently ranked in the top 3 by both providers and patients (Fig. 1). Otherwise, patients and providers appeared to focus on different aspects of the decision. Providers were more concerned about the impact of radiation on the success of the reconstruction than patients (60% vs. 24%, 95% confidence interval (CI) of the difference: −64, −8). Thirty percent of providers placed the fact that women who do not have reconstruction are equally satisfied as women who have reconstruction in the top 3, whereas almost no patients did, and this difference was statistically significant (30% vs. 5%, 95% CI: −47, −3). For all 3 of the facts about immediate versus delayed reconstruction, women placed a higher priority on these facts than providers did. Patients also tended to place more importance than providers did on understanding that the data on complications is limited (24% vs. 5%, 95% CI of the difference: −2, 39).

To look further into the issues of radiation, timing of reconstruction, and limited data on complications, we examined patients' and providers' ratings of these facts (on a 4-point scale). For the fact "radiation can increase complications and affect the look and feel of the breast," 80% of patients versus 100% of providers (95% CI:

TABLE 2. Patient Sample Characteristics (N = 21)

Mean age	50 (range, 35–69)
Mean time since diagnosis	2.7 years
Race (white)	92%
Education (high school or less)	15%
Treated with reconstruction	85%*

*Treatment data were available for 13 of the 21 patients.

TABLE 3. Provider Sample Characteristics (N = 20)

Mean age	43 (range, 32–58)
Time in practice	15 yr (range, 5–38)
Median yearly volume	42 patients
Gender (male)	7%
Specialty	50% physician, 50% plastic surgeon*

*Percentage of the physicians.

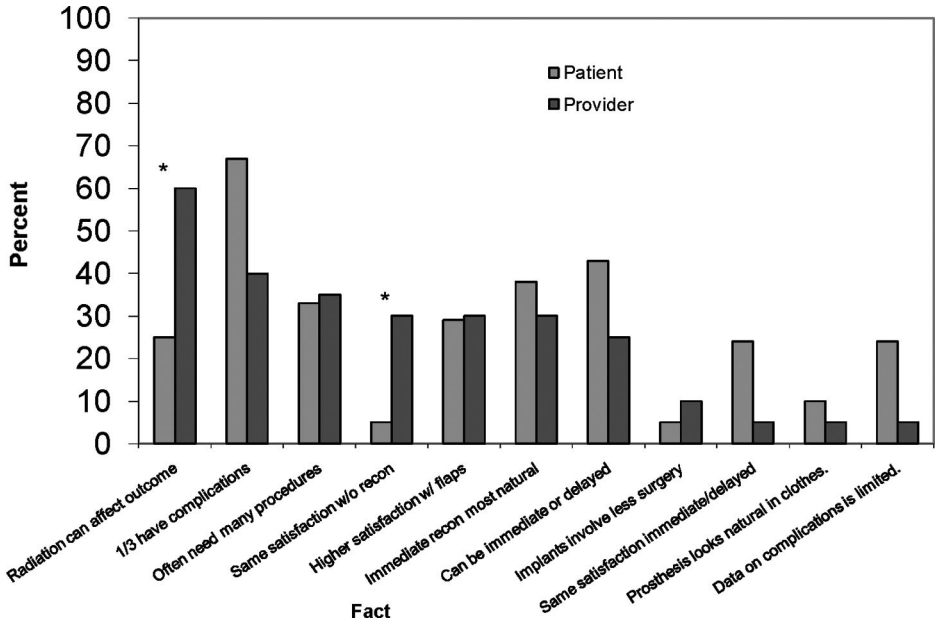

FIGURE 1. Percentage of patients and providers who place a fact in their top 3 (*$P < 0.05$).

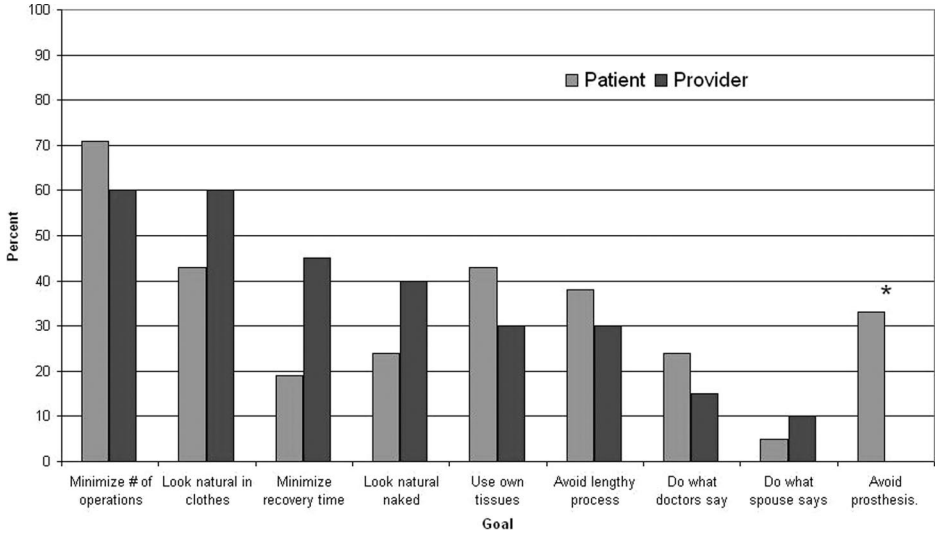

FIGURE 2. Percentage of patients and providers who place a goal in their top 3 (*$P < 0.05$).

−45.1, 1.5) rated the fact as very or extremely important. For the fact "women who delay reconstruction are just as satisfied", 100% of patients versus 64% (95% CI: 24.0, 34.0) of providers rated this as very or extremely important. For the fact "the data available to provide estimates of complications for reconstruction is limited," 71% of patients versus 50% of providers (95% CI: 7.8,−50.6) rated this as very or extremely important.

For providers, the 3 most important facts were:

1. Radiation therapy after mastectomy can increase complications and affect the cosmetic result.
2. About one-third of women who have reconstruction will have a major complication.
3. Reconstruction often requires multiple procedures over multiple visits to complete.

For patients, the 3 most important facts were:

1. About one-third of women who have reconstruction will have a major complication.
2. Reconstruction can often be completed at the same time as the mastectomy or delayed.
3. Immediate reconstruction offers more natural look and feel than delayed.

Ranking and Rating of Goals

The 2 most frequently selected goals were the same for patients and providers: "minimize the number of operations" and "look natural in clothes" (Fig. 2). Patients placed greater importance on avoiding a prosthesis (33% vs. 0%, 95% CI of the difference: 13, 54). There was a trend toward less patient concern about "looking natural without clothes" compared with providers (24% vs. 40%, 95% CI of the difference: −12, 44).

To look further into the issues of avoiding a prosthesis and looking natural in clothes, we examined the ratings of these goals (on a 4-point scale). For the goal "avoid using a prosthesis," 77% of patients versus 30% of providers (95% CI: 13.6, 69.3) rated this as very or extremely important. For the goal "look natural in clothes," 76% of patients versus 85% of providers (95% CI: −15.2, 32.8)

rated this as very or extremely important. For the goal "look natural without clothes", 33% of patients versus 80% of providers (95% CI: −73.4, −20.0) rated this as very or extremely important.

For providers, the most important goals were:

1. Minimize the number of surgeries.
2. Look natural in clothes.

For patients, the most important goals were:

1. Minimize the number of surgeries.
2. Look natural in clothes/use your own tissue.

DISCUSSION

Substantial variability existed among patients and between patients and providers, regarding the most important facts for breast reconstruction decisions. Every item was ranked in the top 3 most important by at least one participant, and no item was ranked in the top 3 by all participants.

Patients placed importance on the fact that reconstruction can be performed immediately or delayed, and the fact that satisfaction is similar for immediate or delayed reconstruction. These findings suggest that plastic surgeons should inform patients about both immediate and delayed reconstruction, even when seeing newly-diagnosed breast cancer patients prior to mastectomy. Referring clinicians, such as surgical oncologists and general surgeons, also should inform patients about timing options for reconstruction.

A third of patients placed "avoid using a prosthesis" in the top 3 concerns, whereas not a single provider did. Similarly, fewer patients (25%) than providers (60%) ranked "radiation can affect the outcome of reconstruction" in the top 3. Other studies have also found that not having to wear a prosthesis is a major consideration for women considering or reflecting on breast reconstruction.[5,6]

Patients may be less concerned than providers realize about how the reconstructed breast appears without clothing. Fewer patients (24%) than providers (40%) ranked the goal of looking natural without clothing in the top 3 (although this difference was not statistically significant). Other studies' findings regarding the importance of scarring to patients have been somewhat mixed.[5,7] We recommend that plastic surgeons specifically ask patients how concerned they are about the appearance of their breasts in clothing versus without clothing.

Both patients and providers ranked highly the fact about complications. The specific complication rate of one-third was based on the largest multisite cohort study of reconstruction patients in the literature,[8] but specific providers' complication rates are likely to vary. Nonetheless, patients clearly felt that factual information about complication rates was highly important for decisions about reconstruction.

Limitations of this study arise primarily from the use of small, nonrandom samples. Patients tended to be white and well-educated, and most had undergone reconstruction. Because of the small sample sizes, we are not drawing final conclusions about patient or provider opinion but are suggesting areas for further research and for consideration by plastic surgeons in the counseling of patients.

Significant variability exists among patients and between patients and providers, with respect to the most important facts and goals to guide decision making about reconstruction. Providers should ensure that women understand that reconstruction can be done immediately or delayed, as well as the likelihood and type of complications, including the number of surgeries that may be required. Because women vary in their goals and concerns, surgeons should ask each woman which goals and concerns are most important to her. Specifically, they should inquire as to how women feel about using a prosthesis, and how they feel about their appearance with and without clothes.

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