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CLARIFYING THE EXPECTATIONS OF PATIENTS UNDERGOING IMPLANT BREAST RECONSTRUCTION: A QUALITATIVE STUDY

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Abstract

Background—Unfulfilled expectations can lead to patient dissatisfaction with surgical outcomes. Understanding expectations allows surgeons to identify those patients who hold inaccurate expectations preoperatively, and to reset those expectations through focused preoperative education. The purpose of this study is to investigate preoperative expectations of women undergoing implant breast reconstruction. Identifying inaccurate or unfulfilled expectations is a critical step towards the advancement of preoperative education and subsequently improving patient satisfaction with surgical outcomes.

Methods—In-depth, open-ended interviews were conducted with 28 women undergoing implant breast reconstruction. The interviews were recorded, transcribed, and data were coded using standard qualitative techniques.

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Results—Interviews ascertained that implant-based breast reconstruction patients may have inaccurate expectations regarding the results of their surgery despite having received standard preoperative teaching. Specifically, patients often had unclear expectations regarding the appearance and physical outcome of the reconstructed breast(s). Some patients were surprised by the “flatness” of the tissue expander immediately following its insertion. Most patients felt unprepared for the “unnatural” final appearance of the breast(s). Furthermore, they did not expect many of the physical outcomes, including loss of sensation, firmness of the reconstructed breast(s), and lack of movement of the reconstructed breast(s). Inaccurate expectations corresponded to areas of dissatisfaction highlighted by the patients in postoperative interviews.

Conclusion—This study has important implications for preoperative education of women undergoing implant breast reconstruction. Physicians and nurses involved in the preoperative preparation process should take care to explore patients’ expectations regarding the look, feel, sensation, and movement of reconstructed breasts to increase overall postoperative satisfaction.

Keywords

Satisfaction; Expectation; Breast Reconstruction; Implant; Quality of Life; Mammoplasty; Breast Implant

INTRODUCTION

Unrecognized or unfulfilled expectations regarding surgical results are associated with patient dissatisfaction as well as poor overall outcome from the patient perspective [1,2,3,4,5]. While patient satisfaction is important in all surgical disciplines, one could argue that patient satisfaction is most important for surgical subspecialties where the overriding goal is to meet patient expectations and improve their quality of life.

Surprisingly, there has been relatively little in the plastic surgery literature describing women’s expectations of breast reconstruction [6,7]. Rowland et al. interviewed women undergoing delayed breast reconstruction and asked them to rate a variety of expectations statements regarding the anticipated psychosocial benefits from their upcoming breast reconstruction [6]. The statements used were created in an ad hoc manner for this specific study. They concluded that women who expected their reconstruction would improve sexual relations and other relationships were less satisfied post-reconstruction. More recently, Brandberg et al. designed an ad hoc questionnaire to assess women’s psychosocial expectations prior to breast reconstruction, finding that in general women had high expectations of the psychological benefits from their reconstruction [7]. Surprisingly, there have been no published studies addressing women’s expectations of the appearance, feel, or movement of the reconstructed breast.

In-depth communication between the surgeon and the patient is sometimes difficult to accomplish in a busy clinic setting. To maximize patient benefit, accurate and relevant information must be provided to the patients preoperatively in a clear and efficient manner. This is only possible if the surgical team knows precisely what information needs to be communicated to the patient. This can be difficult to achieve, as it has been demonstrated in the plastic surgery setting, a surgeon’s opinion of what information is most important to the

patient may be quite different than the opinion of the patient receiving the information [8]. For example, the surgeon may assume the patient knows they will lose sensation in their breasts, while the patient may not have even considered loss of sensation as a potential outcome.

The purpose of this study was to investigate expectations of women undergoing implant-based breast reconstruction after having received standardized preoperative teaching. Through open-ended interviews with patients both before and after breast reconstruction, we sought to identify commonly occurring expectations that are inaccurate or poorly developed. This study is part of a larger project being performed to develop a questionnaire to formally evaluate patient expectations prior to breast reconstruction surgery. Data gathered from patient interviews is being used to create the content of the questionnaire. It is hoped that a better understanding of patient expectations may enable surgeons and surgical educators to provide efficient and effective preoperative education to promote realistic expectations.

METHODS

Study Design & Patient Recruitment

Local institutional ethics review board approval was obtained for this study. Women planning to undergo breast reconstruction following a mastectomy for breast cancer were invited by mail to participate in an interview. This study is part of a larger project exploring expectations of both alloplastic and autologous breast reconstruction. Women involved in this study are a subsample of all of the women enrolled in the larger Evaluating Expectations for Breast Reconstruction project (NIH grant # 5R03CA128476-02). Women were eligible if they had or were planning on having breast reconstruction surgery at Memorial Sloan Kettering Cancer Center by one of five participating plastic surgeons, if they had not previously had breast reconstruction, spoke English and were between the ages of 18 and 75 years old. All interviews were performed after completion of the standard preoperative education process at the investigating institution. The standard preoperative education process involves an in-depth consultation with the surgeon, individualized teaching session with the clinic nurse, and the option to attend a four hour breast reconstruction information class given by the clinic nurses prior to surgery. As the breast reconstruction information class is optional, it was not recorded whether or not the patients actually attended the session.

Interview Framework

A one-page interview guide was developed (see Figure 1 for an example). Interviews commenced by asking the participant to discuss the circumstances that led to her decision to have surgery. Participants were thereafter encouraged to discuss their expectations as completely as possible using their own words. Interviews lasted 60 minutes on average. Trained interviewers conducted the interviews. All interviews were digitally recorded and transcribed verbatim by a professional transcription service.

Data Analysis

Data were collected and analyzed in an iterative manner, alternating between data collection and coding, in order to develop a rich and variable understanding of emerging content. Data analysis focused on domains and themes related to participants' expectations for outcomes associated with breast reconstruction. Open coding, the first step in the analytic process, involved generating initial codes and categories through a line by line analysis of a subset of interview transcripts. Initial categories were identified and coding was conducted by a research team member with experience in qualitative data analysis. Codes and categories were refined and new ones were generated through an iterative method as new transcripts were examined. Coding software was used to organize items (Nvivo 7.0). The coded statements were used to develop conceptual categories.

RESULTS

Patient Demographics

Twenty-eight women underwent in-depth interviews evaluating expectations for outcomes associated with their breast implant reconstruction surgery. Of the women interviewed, 11 underwent interviews both pre- and post-reconstruction; 4 women had interviews pre-reconstruction only; 7 had interviews after the insertion of the tissue expander but prior to the implant exchange; 6 had interviews after the TE-implant exchange. All reconstructions were immediate. Average age was 49 years. Twenty-seven of the twenty-eight patients underwent reconstruction secondary to a cancer diagnosis. One patient had a prophylactic mastectomy due to the BRCA2 gene mutation. Post-reconstruction interviews were done on average 13 months after the last reconstruction surgery (range 1–58 months).

Identified Key Themes

Four key themes identified from the interviews: i) Appearance & outcome of breasts, ii) Physical impact of reconstruction, iii) Process of care and recovery, and iv) Psychosocial impact of reconstruction. Common unrealistic or unclear expectations from all domains are summarized in Table 1. Expectation statements falling under the key theme "Psychosocial impact" were not unique to implant reconstruction; therefore, for the purposes of this paper will not be discussed.

i) Appearance & Outcome of Breasts

• **Scarring:** Most women expected scars on their breasts post-reconstruction. However, patients were unclear about the length of the incisions, and the natural progression of scar maturation.

"I was horrified, because if I would have known that there were going to be six to eight inches of additional scarring on both sides, I might not have done that... I wasn't mentally prepared for that."

• **Overall Appearance:** Expectations with regards to the look of the breasts in clothing were much more clearly described than the look of the breasts out of clothing. Women were frequently unprepared for the appearance of their breasts when unclothed.

“I assume that I should be able to wear all the same clothes that I did; that I should look the same in a sweater or whatever.”

“I suppose you will look normal, you know, maybe if you are completely naked.”

• **Shape, Symmetry, and Natural Look:** Specific expectations with regards to the shape, symmetry and natural appearance of the breast were often unclear and unrealistic. Particularly, patients seemed to have high expectations about the shape and the overall natural look of the breast.

“I expect it to come close to my natural shape.”

When these high expectations were not met, patients expressed dissatisfaction and disappointment:

“I thought it would have more of a natural droop.”

“I thought I was going to get back these perky little boobs and I have these big matronly things.”

“It doesn’t look as natural as I was expecting... it doesn’t look natural at all.”

When asked how they created these expectations, patients often referred to the Internet, books, and friends as being the main sources of information. In other words, preoperative visits with the surgeon and the nurse educator were not necessarily the most influential sources in creating expectations regarding the appearance of the reconstructed breast.

ii) Physical Impact of Reconstruction

• **Feel to the Touch:** Patients conveyed uncertainty about how the breast(s) would feel to the touch, using words such as “hoping”, “I guess”, and “I imagine” when describing their expectations.

“I’m just hoping that it’s going to feel more or less like the other breast.”

Patients that were unclear about expected results preoperatively described disappointment postoperatively.

“I thought it would be closer to a regular breast in terms of feel but it’s not.”

“I didn’t know that it would be as hard as it is.”

“The fact that if you turn over in bed on them and you feel like you’re on two very hard pillows under each side, I was not expecting.”

• **Sensation:** There was a wide range of expectations about sensation in the reconstructed breast(s), leading to surprise and dissatisfaction in some women.

“I wasn’t expecting that when I would touch my skin I wouldn’t feel anything at all. There is no sensation there and I wasn’t ready for that.”

“The sensation is something that I think will recover with time.... I feel that it will all come back eventually”

• **Response to Temperature Changes:** Women were surprised by the discomfort of their implants in cold temperatures. As this was frequently not expected, women often described the cold feeling in their breasts in cold weather as alarming, and wondered why they had not been forewarned.

• **Movement:** The movement of the reconstructed breast is one physical aspect of the reconstruction that was very much under-addressed in the preoperative period. These interviews revealed that it was a source of concern postoperatively.

“I did expect them to be more—they don’t move... so I guess I wouldn’t have expected them to move more-- I knew that the tissue expanders were like that. I expected the permanent implants to have a little bit more movement.”

In fact, many women interviewed postoperatively mentioned specific daily activities that were now (unexpectedly) uncomfortable for them, including hugging others, lying on their stomach, leaning over, and even laying on their back.

• **Foreign Body Sensation:** Many women expected ultimately to be unaware of the reconstructed breast, assuming that it would eventually feel like a part of their body. While this may be the case for some women, it is not true for all women. This ‘foreign body sensation’ was a source of concern and distress for women, largely due to the fact that it was so unexpected.

“I didn’t expect to always think of it, to always be reminded of it and always have it in my mind. I thought it would just eventually feel like part of me. And it doesn’t.”

“I’m pretty much always aware that there’s something there. So if it is the case it would be nice if they sort of told you--you’re just going to feel this.”

iii) Process of Care & Recovery—This key theme refers to process of care issues, including the tissue expansion process itself, the number of clinic visits and surgeries, and complications. Patients interviewed preoperatively were able to clearly state how often they expected to be seen for expansions, and had clear expectations with regards to the purpose of these expansions:

“Just to kind of form the breast again, to get the muscles and skin acclimated, because nothing’s going to be there, so it has to form again. That’s my understanding.”

While most women could explain the process of inserting an expander and inflating it to create a mound or a breast shape, they often did not expect what they would see when waking from anesthesia:

“I thought when I woke up from anesthesia I would see a breast.”

This expectation of seeing a breast or a fully formed mound after the tissue expander insertion was a source of great disappointment and emotional distress in the initial postoperative period for some women.

In general, women also communicated an appreciation of the potential for both short term and long term complications.

“I felt, you know, not comfortable with the idea that I could have infection. But not uncomfortable enough that I wouldn’t do it.”

“All these things will happen, but I think, you know, I realize that it’s a surgical risk that he has to go over all that. So it’s not a surprise later on.”

Standard preoperative teaching thus was generally able to create clear expectations of the logistics of the tissue expansion process and the potential for complications.

DISCUSSION

The goal of this research was to identify those patient expectations for implant breast reconstruction that are commonly unclear and unrealistic. In this qualitative study of 28 patients, we found that patients did not have clear and accurate expectations regarding certain aspects of the appearance and physical impact of their breast reconstruction. These unclear expectations frequently contributed to postoperative dissatisfaction.

Regarding breast appearance, many women were surprised that they did not see a fully or partially-formed breast upon awakening from anesthesia following the insertion of the tissue expander. Expectations of the appearance of the reconstructed breasts when unclothed ranged from “better than before” to “look like a freak”. Expectations about breast shape and whether the reconstructed breast would appear “natural” were also not adequately explained or clarified preoperatively. These aspects of breast appearance should therefore be highlighted during preoperative discussion with women.

The most difficult topic to discuss with patients may be the physical impact of reconstruction. Apart from the expected decrease in skin sensation, surgeons may not pay as much attention to the physical sensations that women experience once they have undergone their reconstruction. Specifically, patients may wonder how their reconstructed breasts are going to feel under clothing, during movement, when laying down, when leaning over, when hugging others, or when going out in cold weather. One cannot underestimate the importance of being emotionally prepared for these physical changes. As a result, these physical experiences are a major source of dissatisfaction postoperatively, with patients often commenting, “If I had known before, it wouldn’t bother me so much...”.

A failure to guide patients toward accurate expectations for the look and feel of their reconstructed breast(s) may force them to gather information from other resources such as family, friends, media, the Internet, and their own previous experiences. Commonly, for example, patients assume that the results of implant-based breast reconstruction are the same as those from a cosmetic breast augmentation. They assume that their reconstructed breasts will move, feel, and look the same as their natural breasts but simply an enlarged version.

The information from this study can be used to create concise but comprehensive communication between the patient and their surgeon preoperatively. This qualitative exploration of patient expectations will be used to develop a questionnaire that may be used

to quantitatively evaluate preoperative expectations of women undergoing breast reconstruction. More accurate and useful information using language that resonates with the patients would create more realistic expectations, hopefully avoiding the dissatisfaction or disappointment of having an outcome that is not quite what they had envisioned.

CONCLUSIONS

This study has important implications for preoperative education of women undergoing implant breast reconstruction. Physicians and nurses involved in the preoperative preparation process should take care to explore patients' expectations regarding the look, feel, sensation, and movement of the reconstructed breasts to increase their postoperative satisfaction in those domains. Questionnaires and preoperative teaching that formally evaluate and address patient expectations may therefore play an important role in increasing patient satisfaction postoperatively.

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Goal of Interview:

The patients being interviewed here have already undergone an in depth preoperative interview exploring their expectations of the breast reconstruction experience. The goal of this interview is to follow-up with a group of patients that have undergone implant based breast reconstruction and have been through the tissue expansion process. The focus of the interview will be to assess how their experience differed from their preoperative expectations.

Interview Questions:**I. Intro/Background Questions**

- Tell me a little of your story-

II. The process of tissue expansion

- How well prepared were you for the appearance of your chest after your TE insertion?
- How did you feel about the idea of gradual expansion of the tissue expander? Did you talk to other people about this? How did they feel about the TE concept?
- Was there anything in particular that surprised you about the tissue expansion process specifically?
- Were you well prepared mentally for this process?
 - How could we have prepared you more? What could you have been told or shown etc that would have prepared you better?

III. Surprises/ things not expected

- Is there anything that surprised you or that you wish you had known about the whole tissue expansion process or the implant type of breast reconstruction?
 - Length of the process
 - Final appearance
 - Feel
 - Movement
 - Etc

IV. Patient satisfaction with appearance

- How do you feel about the appearance of your reconstructed breast(s)?
- What did you expect?

V. What would you tell a doctor to do in order to best prepare someone for this process?**Figure 1.**

Interview Guide for expectations of the tissue expansion process and outcome in breast reconstruction patients- postoperative patients

Table 1

Summary of Unrealistic or Unclear Preoperative Patient Expectations

Major Theme	Subtheme	Common Expectations for the Reconstructed Breast(s)
Appearance & Outcome of Breasts	Scarring	Unclear about size, shape, number of scars
	Overall Appearance, unclothed	Ranged from “better than my natural breasts” to “look like a freak”
	Shape, Symmetry, and Natural Look	Natural shape, natural droop, breast symmetry
Physical Impact of Reconstruction	Feel to the Touch	Similar to the natural breast(s)
	Sensation	Still some sensation left; most sensation will return
	Response to Temperature Changes	No awareness of implants in response to cold weather
	Movement	Natural movement
	Foreign Body Sensation	Implants will feel like a natural part of their body; they will have no awareness of their implants