

Met and Unmet Expectations for Breast Reconstruction in Early Posttreatment Breast Cancer Survivors

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The purpose of this study was to evaluate the prevalence of met and unmet expectations after breast reconstruction among breast cancer survivors following mastectomy. A secondary objective was to examine reasons women report their experiences of reconstructive surgery were better or worse than expected. As part of a larger study of breast cancer survivors, participants completed self-administered questionnaires within 8 months of diagnosis and at 6, 12, and 18 months later. At the 18-month follow-up, women who had breast reconstruction were asked whether their reconstruction was better, the same, or worse than expected. The sample consisted of 130 survivors (mean age = 48.5 years) who had breast reconstruction

following mastectomy and completed the 18-month follow-up, 42% of whom reported their reconstruction was worse than expected and only 25% reported it was better. Most frequently reported reasons for reconstruction being worse than expected were related to appearance of the reconstructed breast and pain. A high percentage of patients with breast cancer undergoing breast reconstruction following mastectomy reported the results as worse than expected, with the primary reasons for dissatisfaction related to the feel and appearance of the reconstructed breast. Patients with breast cancer considering breast reconstruction need better preoperative education or understanding about what to expect from reconstruction.

Each year more than 100,000 women in the United States undergo some form of mastectomy for the surgical treatment of breast cancer (American Cancer Society, 2016). Of those who undergo mastectomy, an estimated 25%–50% elect to have breast reconstruction (Greenberg et al., 2011; Kruper et al., 2011; Morrow et al., 2014). The goal of breast reconstruction is to restore a breast mound and to maintain quality of life without affecting the prognosis or detection of cancer recurrence (Cordeiro, 2008). Women often undergo breast reconstruction to feel normal and improve self-esteem (Flitcroft

et al., 2016; Flitcroft, Brennan, & Spillane, 2017). However, longitudinal studies suggest that for some women, breast reconstruction may be associated with worse psychological functioning (Metcalf et al., 2015; Nissen et al., 2001) and dissatisfaction with body image (Eltahir et al., 2013; Howes et al., 2016; Metcalf et al., 2012). Recovery time, degree of pain, and aesthetic outcomes can have a significant impact on quality of life (Spector, Mayer, Knafel, & Pusic, 2011; Winters, Benson, & Pusic, 2010; Zhong et al., 2012). Extant data suggest that many women have unmet information needs (Harcourt et al., 2003; Lee, Hultman,

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& Sepucha, 2010; Rolnick et al., 2007; Snell et al., 2010) and/or may have unrealistic expectations about recovery from reconstructive surgery and the potential for breast reconstruction to improve well-being (Flitcroft et al., 2016; Nissen, Swenson, & Kind, 2002).

The primary objectives of the present analyses were to (1) to examine rates of met and unmet expectations in a sample of breast cancer survivors who underwent breast reconstruction following mastectomy and (2) examine reasons women report their experience of reconstructive surgery as better or worse than expected. In addition, we describe reasons for met and unmet expectations based on type of reconstruction. Results are intended to inform clinicians of the expectations of patients with breast cancer considering breast reconstruction regarding potential benefits and problems associated with breast reconstruction.

METHODS

Participants and Procedure

The present analyses were derived from a longitudinal, observational study to examine age differences in adjustment to breast cancer that was conducted among women who were newly diagnosed with Stage I, II, or III breast cancer (Avis et al., 2012, 2013). Study eligibility criteria included first-time breast cancer diagnosis, at least 18 years of age at diagnosis (although no participant was younger than 25 years), and ability to read and understand English. Recruitment was conducted at Memorial Sloan Kettering Cancer Center and the University of Texas–Southwestern Center for Breast Care from 2002 to 2006. Women were recruited through hospital clinics and advertisements and were initially screened by medical record review or telephone for eligibility.

Eligible women were mailed a baseline questionnaire to complete and send to the Coordinating Center at the Wake Forest School of Medicine. Baseline questionnaires were completed within 8 months of diagnosis. Follow-up surveys were sent 6, 12, and 18 months following completion of the baseline survey. The present analyses use baseline data and breast reconstruction expectation data collected at the 18-month survey. Patients were considered eligible for the present analyses if they had undergone unilateral or bilateral mastectomy, had breast reconstruction, and completed questionnaires at both time points. Institutional review boards at each of the participating institutions approved this study.

Measures

Reconstruction Results and Expectations

Patient's expectations about reconstruction were assessed at the 18-month follow-up through the question: "How did your expectations before treatment compare with the actual treatment you received?" Response options included

worse than expected, same as expected, better than expected, or not applicable. Women who selected worse or better than expected were asked to provide an open-ended response explaining why.

Sociodemographic Variables

Sociodemographic information included age, race (non-Hispanic White/other), married/partnered (yes/no), employment status prior to diagnosis (full-time/part-time employment/none), education (high school graduate or less/some college/4-year college graduate/postgraduate work), and ability to pay for basics (somewhat or very hard/not hard).

Cancer-Related Variables

A comprehensive medical record review was performed by the research staff following the patient's completion of adjuvant therapy and included surgical procedures and treatments related to cancer diagnosis. The following variables were included in study analyses: time between diagnosis and baseline questionnaire, cancer stage at diagnosis, radiation therapy (yes/no), and chemotherapy (yes/no). Reconstruction was documented by medical record review for the majority of women ($n = 113$) and by self-report for women who began reconstruction after the medical record reviews had been completed ($n = 17$). Reconstruction method was self-reported.

Data Analysis

Responses to open-ended questions were examined according to whether women responded that their reconstruction was better than expected, worse than expected, or same as expected. On the basis of predominant themes and repetition of key issues, one coauthor (A.J.) developed general categories for responses. These categories included appearance, pain (or lack of) discomfort (or lack of), recovery time/healing, technical/medical, and emotional well-being. A.J. and B.L. then separately coded participants' response into these categories. With respect to classifying participants' answers into these thematic groups, the two coders had identical agreement except for two answers from two different participants. Upon discussion, they came to agreement on coding these responses. Many participants provided more than one response, so the total number of responses across the categories sums to more than the number of participants. All quantitative analyses were conducted using SAS 9.3 (SAS Institute, Inc., Cary, NC).

RESULTS

Sample Characteristics

A total of 740 surveys were mailed to patients deemed eligible from medical record reviews; 653 women completed

the baseline survey, for a response rate of 88%. Of these 653 women, 565 remained in the study at the 18-month follow-up (86.5%); of those, 237 received mastectomy and 157 underwent breast reconstruction. Of the 157 women who had breast reconstruction, 130 (83%) completed the 18-month follow-up and responded to the questions on expectations. Type of reconstruction was available for 103 women (79.2%).

Table 1 shows characteristics for the sample that had reconstruction and completed the 18-month questionnaire ($N = 130$). These women were mostly White (94%), reported little difficulty paying for basics (85%), were predominantly college-educated (72%), and married/partnered (79%). The majority of women (66%) were employed prior to diagnosis. Most of these women were diagnosed with Stage I or II cancer (91%) and had received chemotherapy (84.6%), whereas 29% had received radiation. Mean age at diagnosis was 48.5 years ($SD = 11.2$ years).

Reported Expectations

More women reported that their breast reconstruction was worse than expected (42.3%) than better (25.4%) or same as expected (32.3%) (Table 2). Of those who had known breast implants (type of reconstruction was unknown for 27 women), 43.8% ($n = 39$) rated reconstruction worse than expected, 34.8% ($n = 31$) rated reconstruction the same as expected, and 21.4% ($n = 19$) rated it as better than expected. The number of women who had known autologous tissue reconstruction was small, and percentages should be viewed cautiously. Of those who had known autologous tissue, 50% ($n = 7$) rated reconstruction as worse than expected, 14.2% ($n = 2$) rated it the same as expected, and 35.7% ($n = 5$) rated it better than expected.

Reasons Why Reconstruction Was Worse Than Expected

Among the 55 women who rated reconstruction as worse than expected (implants: $n = 39$; autologous: $n = 7$; method unverified: $n = 9$), five key themes were identified: (1) appearance/feel, (2) pain, (3) discomfort (4) healing/recovery time, and (5) technical considerations.

TABLE 1 Baseline Characteristics of Sample	
Variable	<i>n</i> (%)
<i>Sociodemographic variables</i>	
Caucasian	122 (93.9)
Difficulty paying for basics	
Somewhat/very hard	19 (14.6)
Not hard	111 (85.4)
Education	
High school graduate or less	8 (6.2)
Some college	28 (21.5)
College graduate	32 (24.6)
More than college graduate	62 (47.7)
Married/partnered	103 (79.2)
Employed prior to diagnosis	86 (66.2)
<i>Cancer-related variables</i>	
Stage	
I	43 (33.1)
II	75 (57.7)
III	12 (9.2)
Radiation	38 (29.2)
Chemotherapy	110 (84.6)
Reconstruction type	
Implant	89 (68.5)
Autologous	14 (10.8)
Unknown	27 (20.8)
	Means (SD)
Age at diagnosis	48.5 (11.2)
Time from diagnosis to baseline survey (months)	4.4 (1.3)

The number and percentages of women who gave reasons for these categories are shown in Table 3.

Appearance

Among the 39 women who had implants and rated reconstruction as worse than expected, 53.8% ($n = 21$; Table 3)

TABLE 2 Number of Women With Met and Unmet Expectations by Reconstruction Method ($N = 130$)			
	Worse Than Expected ($n = 55$; 42.3%)	Same as Expected ($n = 42$; 32.3%)	Better Than Expected ($n = 33$; 25.4%)
Reconstruction type			
Implant ($n = 89$)	39 (43.8%)	31 (34.8%)	19 (21.4%)
Autologous ($n = 14$)	7 (50.0%)	2 (14.2%)	5 (35.7%)
Unknown ($n = 27$)	9 (33.3%)	9 (33.3%)	9 (33.3%)
<i>Note.</i> Percentages are row percentages.			

TABLE 3 Number (%) of Women Giving Reasons Reconstruction Was Worse Than Expected, by Reconstruction Method

Reason Category	Total (N = 55)	Implant (n = 39)	Autologous Tissue (n = 7)
Appearance/feel	28 (50%)	21 (53.8%)	2 (28.6%)
Pain/lack of	14 (25%)	7 (17.9%)	1 (14.3%)
Discomfort/lack of	11 (19.6%)	11 (28.2%)	–
Healing/recovery time	11 (19.6%)	6 (15.4%)	3 (42.9%)
Technical	10 (17.9%)	4 (10.3%)	3 (42.9%)
Emotional well-being	–	–	–

Note. Column *n*'s do not sum to the column headings because women could provide multiple reasons for why reconstruction did not meet their expectations. Nine of the 55 women who rated reconstruction as worse than expected did not have a confirmed reconstruction method in the data set. These women were included in the "Total" column.

cited appearance-related concerns. These expectations focused on unnatural appearance and lack of breast symmetry:

- More unnatural appearance than expected.
- It's too lumpy and more firm than my natural breast.
- Results don't look very real to me.
- Have a hard blob very different than my other real breast.
- Feels harder than a real breast.
- Appearance worse than expected. Not symmetric.
- Not as symmetrical as I would have liked.
- Side does not match.
- Lack of symmetry, poor appearance.
- Breasts different sizes—hard to find bras.

Among the seven women who had autologous tissue and rated reconstruction as worse than expected, only two women cited appearance-related concerns:

- Breast was up on my shoulder.
- Nipple disfigurement.

Pain

Pain was cited by 25% ($n = 14$) of the women who rated reconstruction as worse than expected. Among the 39 women with implants who rated reconstruction as worse than expected, 17.9% ($n = 7$) made reference to pain:

- I expected it to not be such a big deal but was surprised at how painful.
- The fills for the tissue expanders were very painful for me!

Among the seven women who had autologous tissue and rated reconstruction as worse than expected, only one made reference to pain: "Pain was much worse."

Discomfort

Discomfort was cited by 19.6% of the women who rated reconstruction as worse than expected but by 28% of those with known implants. None of the women with known autologous reconstruction provided discomfort as a reason.

- Implant was uncomfortable.
- Discomfort of tissue expander.

Expander was uncomfortable.

Getting the expander filled was very uncomfortable.

The fills for the tissue expanders were very painful for me!

Healing and Recovery

Concerns related to healing and recovery time were cited by 19.6% ($n = 11$) of the women who rated reconstruction as worse than expected. This was one of two primary reasons provided by the women who had known autologous reconstruction, with 42.9% ($n = 3$) of these women giving recovery time as a reason. This was a less cited reason among the 39 women who had implants, with only 15.4% ($n = 6$) citing this reason. Comments related to healing and recovery were similar among those who had implant versus autologous tissue:

- The permanent implant not as nicely healed as the temporary implant due to radiation effects.
- The healing process was 3 months long.
- Took longer to complete than expected.
- I did not expect it to be a long process.
- Long recovery.
- One-time surgery became three.

Technical

Technical aspects of surgery were cited by 17.9% ($n = 10$) of women who said reconstruction was worse than expected and was a primary reason cited among those who had autologous reconstruction, with 42.9% ($n = 3$) citing this reason.

- Scar tissue required a redo.
- Nearly died due to hemorrhage from reconstruction; bedside manner needs improved.
- Surgeon mistakenly raised wrong breast.
- One-time surgery became three!

Reasons Why Reconstruction Was Better Than Expected

Six key themes were identified among those who rated breast reconstruction as better than expected ($n = 33$): (1)

appearance/feel, (2) lack of pain, (3) lack of discomfort, (4) healing/recovery time, (5) technical considerations, and (6) emotional well-being. The number and percentages of women who gave reasons for these categories are shown in Table 4.

Appearance

Appearance was by far the primary reason given by women who said that reconstruction was better than expected, with 80% of women reporting that reconstruction was better, citing this reason. Among the 19 women who had implants and rated it as better than expected, 11 cited appearance.

I truly look normal in my clothes, including a bathing suit.

I didn't expect my reconstructed breast to look anything near normal.

My implant is beautiful because I went to a breast specialist.

I like my new bust better than the one I had.

All five of the women who had autologous tissue and rated it as better than expected mentioned appearance.

Recovery was hard, but the results are much better than expected. Looks and feels very natural.

Tram flap with abdominal muscle provided a very natural look.

Other Reasons

Among the women who had implants, two cited recovery time and healing ("Healed faster," "Easy recovery"), one cited technical aspects ("Good instructions were given"), and one cited emotional well-being ("I feel much better").

DISCUSSION

Results of this study suggest that a large proportion of breast cancer survivors have unmet expectations

surrounding reconstruction after mastectomy, particularly in relation to appearance. Approximately 40% of women who underwent breast reconstruction after mastectomy reported their reconstruction to be worse than they expected (compared with 25% who reported it was better). Although we also queried expectations regarding other forms of treatment (e.g., chemotherapy, radiotherapy, mastectomy), breast reconstruction was clearly the aspect of treatment that failed to meet women's expectations based on the frequency of unmet expectations. Chemotherapy was the next most frequently reported aspect of treatment that failed to meet expectations, with 29.3% of women reporting that it was worse than expected. Breast reconstruction was the only aspect of treatment for which more women rated it as worse than expected than better than expected. This may reflect patient preexisting negative expectations about chemotherapy or radiotherapy or may reflect being more informed about what to expect (Pusic et al., 2012, 2017).

In keeping with other reports (Andrade, Baxter, & Semple, 2001; Elder et al., 2005; Frost et al., 2005), appearance was a prominent factor women cited for why reconstruction was better or worse than expected. Appearance-related issues encompassed overall body appearance as well as breast aesthetics such as breast symmetry, shape, or feel. Many of the appearance-related concerns women reported suggest that they did not fully understand how different their reconstructed breast might look or feel from the nonreconstructed breast, particularly after implant-based reconstruction. This is concerning in light of a recent systematic review suggesting that women's desire to feel and look "normal" is the main reason women want reconstruction (Flitcroft et al., 2017). We found that dissatisfaction with appearance was cited more frequently among women who received implant-based reconstruction than among those who received autologous tissue. Although only a small number of women received autologous tissue, only two noted appearance-related concerns. All five of the women who received autologous tissue and who

TABLE 4 Number (%) of Women Giving Reasons Reconstruction Was Better Than Expected, by Reconstruction Method

Reason Category	Total (N = 33)	Implant (n = 19)	Autologous Tissue (n = 5)
Appearance/feel	27 (80%)	11 (57.9%)	5 (100%)
Pain/lack of	2 (5.7%)	–	–
Discomfort/lack of	1 (2.9%)	–	–
Healing/recovery time	3 (8.6%)	2 (10.5%)	–
Technical	2 (5.7%)	1 (5.3%)	–
Emotional well-being	4 (11.4%)	1 (5.3%)	–

Note. Column *n*'s do not sum to the column headings because women could provide multiple reasons for why reconstruction did not meet their expectations. Nine of the 33 women who rated reconstruction as better than expected did not have a confirmed reconstruction method in the data set. These nine women were included in the "Total" column.

rated reconstruction as better than expected cited appearance. This is consistent with a growing body of literature suggesting that women who receive autologous tissue are more satisfied with their breast appearance and feel and specific aesthetic aspects such as nipple naturalness than those who receive implants (Hu et al., 2009; Pusic et al. 2017; Sgarzani et al., 2015).

Although not as prevalent as appearance-related concerns, pain, discomfort, and recovery time also contributed to dissatisfaction with reconstruction. Women who received implants reported unanticipated discomfort and pain, specifically related to tissue expansion. Unanticipated pain and longer recovery times were mentioned regardless of reconstruction type. Women who received autologous tissue cited technical aspects of reconstruction as frequently as they cited healing and recovery time. Our findings related to pain and recovery time align with a recent prospective study of more than 1,500 women who underwent immediate breast reconstruction and found that women experienced substantial physical impairment a year after surgery regardless of autologous or implant-based methods (Pusic et al., 2017). Women may need to better understand the likelihood of multiple operations, longer than expected recovery times, and physical impairment after reconstruction, regardless of reconstruction method (Fallbjork, Frejeus, & Rasmussen, 2012; Spector et al., 2011).

Our study results highlight the need to improve education and informed decision-making about breast reconstruction following mastectomy. Overall, women's knowledge, preparedness, and decision regarding quality-related breast reconstruction are relatively low (Lee et al., 2017; Manne et al., 2016; Pusic et al., 2012, 2017). For example, although women may view their ability to return to normal activities or avoid complications from surgery as important in their decisions, their actual knowledge of these factors as they relate to reconstruction method appears limited (Lee et al., 2011). Of concern, a recent prospective study of more than 100 women found that a majority underwent reconstruction despite endorsing preferences (e.g., desire to avoid complications) that were better aligned with mastectomy alone (Lee et al., 2017).

Increasing a woman's ability to make an informed decision about breast reconstruction presents several challenges. First, providers may lack the necessary data to adequately inform patients of pros and cons of reconstruction. For example, even though the number of implant-based reconstructions has increased dramatically in the past 10 years (Albornoz et al., 2013), surgeons lack evidence from randomized controlled trials to help women identify the best implant (e.g., silicone vs. saline, variable-volume vs. fixed-volume; Rocco et al., 2016). Providers need patient-reported outcomes data to help them evaluate new reconstruction methods (e.g., prepectoral implants; Caputo et al., 2016). Second, women have a short time frame in which to make their decision

about whether to undergo immediate versus delayed reconstruction as well as what type of reconstruction to undergo. Up to half of all women make a decision about surgical treatment during an initial surgical consultation (Fagerlin et al., 2006). Third, women may not know which questions to ask in their preoperative consultation or may ask relatively few questions as to the relative pros and cons of reconstructions methods (Robinson, Venetis, Street, & Kearney, 2016). As preoperative consultations tend to focus more on the risk of complications (Cheng & Losken, 2015; Pusic et al., 2012), the extent to which women's goals and expectations of reconstruction are discussed may depend upon the patient preparing questions beforehand for the consultation.

Studies in which women have reported high satisfaction with breast reconstruction suggest several potential ways to improve patient understanding and set realistic expectations for reconstruction (Elder et al., 2005). First, the range of aesthetic outcomes should be included in preoperative consultations in conjunction with discussions about risk. Second, women may benefit from seeing a multidisciplinary surgical team, including a plastic surgeon, a breast surgeon, and a specialized breast reconstruction nurse. Third, written and video material that includes information from previous patients, including photographs with a range of outcomes, may help prepare women for what they might expect their breasts to look and feel like. Providing women with freely available decision aids (e.g., *Frankly Speaking About Cancer: Spotlight on Breast Reconstruction*; <https://orders.cancersupportcommunity.org>) or interactive Web-based decision aids prior to their surgical consultations may help them prepare questions, explore decisions in relation to personal values, and increase perceived personal control and satisfaction over decisions (Manne et al., 2015; Sherman et al., 2017). After receiving information and considering their own circumstances (e.g., competing time demands, cost, distance to clinic; Flitcroft, Brennan, & Spillane, 2017), some women will decline reconstruction. A recent report suggests that women are increasingly coming forward to publicly express their concerns about breast reconstruction and sharing their reasons for declining reconstruction, referred to as "going flat" (Rabin, 2016). Some women who are declining reconstruction are also turning to tattoos to transform mastectomy scars (Booth, 2015). For women who view reconstruction as an important part of recovery from breast cancer, setting realistic expectations with regard to aesthetic outcomes, pain, and recovery may ultimately yield higher satisfaction (Ho, Klassen, Cano, Scott, & Pusic, 2013; Sgarzani et al., 2015).

Study Limitations

The present study has several limitations. We did not assess expectations prior to surgery and were thus unable to determine the role of preprocedure expectations or

how they changed following surgery. In addition, we are limited in making comparisons between types of reconstruction due to the low number of women who received autologous tissue reconstruction. Although characteristic of many samples of patients with breast cancer, this sample is relatively homogeneous (mostly White, educated), which limits the generalizability of our findings. Ethnic minorities and those with less education may be less informed about reconstruction (Alderman et al., 2009; Lee et al., 2011; Morrow et al., 2014). Future research should examine treatment expectations and satisfaction in more diverse samples. We should also point out that the study was conducted 10 years ago and possible refinements in reconstruction may have improved outcomes. The number of bilateral mastectomies, including contralateral prophylactic mastectomies, and the number of implant-based reconstruction methods have increased over the past 10 years (Albornoz et al., 2013; Cemal et al., 2013). Although women's experiences with specific aspects of surgical procedures may differ today, recent data (Pusic et al., 2017) suggest that the concerns women in our sample raised remain salient and applicable.

CONCLUSION

Appearance, pain, and recovery expectations are salient factors in women's experiences with breast reconstruction. Future prospective studies need to systematically examine the relation between preoperative expectations about breast reconstruction and postprocedure results and how improved communication between health care providers and patients might reduce the discrepancy between expectations and satisfaction with outcomes.

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