

# Barriers to Completing Delayed Breast Reconstruction Following Mastectomy: a Critical Need for Patient and Clinician Education

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**Abstract** Rates of breast reconstruction following mastectomy vary widely, and little is known about why women who originally express an interest in breast reconstruction do not receive it. Improved documentation of clinical decision-making is one of the potential benefits of the electronic health record (EHR), and may serve as a tool to enhance patient-centered, clinical outcomes research. The goals of this study were to explore patterns in delayed reconstruction (DR), identify barriers to follow through, and to determine the adequacy of EHR documentation in providing information about decision-making for breast reconstruction. Retrospective EHR review of women undergoing mastectomy, 2008–2012, was conducted in an academic medical center in New England. Data included patient demographics, cancer stage, co-morbidity index, post-mastectomy reconstruction status, and documented decision-making regarding reconstruction. Of 367 women who had undergone a total mastectomy, 219 did not receive immediate reconstruction. Of these, 24.6 %

expressed no interest in DR, 21.9 % expressed interest but were still pending the procedure, and 5.9 % had completed DR. Of decision-making regarding breast reconstruction, 47.5 % lacked documentation. Median follow-up was 34 months. Reasons for not following through with DR included poor timing (25 %), indecision (17 %), desired method of reconstruction not available at treating facility (10 %), persistent obesity (8.3 %), continued smoking (4 %), and reason not specified (35 %). Many women do not receive breast reconstruction despite expressing an initial interest in the procedure. Reasons were multi-factorial and the extent of documentation was inconsistent. Further exploration of potential barriers to breast reconstruction as well as opportunities to enhance shared decision-making may serve to improve patient experience and satisfaction following mastectomy.

**Keywords** Breast cancer · Breast reconstruction · Decision-making · Quality improvement

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## Introduction

Many women undergoing mastectomy for the management of breast cancer or for breast cancer risk reduction are eligible for some form of breast reconstruction. The choice between immediate reconstruction (IR), delayed reconstruction (DR), and no reconstruction is determined by patient preference as well as by their clinical features and treatment needs.

The factors determining receipt of delayed breast reconstruction (DR) may be an unusual topic for an education journal; however, it breaks some new grounds in opportunities for cancer education and the process of shared decision-making. We aim to improve understanding of why patients who initially voice interest in delayed reconstruction do not ultimately receive the procedure. This information may inform clinicians

on how to best address patient concerns, educate woman about their options, and enhance shared decision-making in breast cancer management. In addition, we take a look at the electronic health record (EHR) and its potential use in documenting clinical decision-making and patient education.

Population-level data of women undergoing total mastectomy demonstrate that among eligible patients only 17 % undergo post-mastectomy reconstruction [1–5]. Other studies distinguishing IR from DR found rates ranging from 4.9 to 53.4 % for IR and 3.1 to 16.8 % for DR [2, 6–8]. There were no *definitive* trends explaining the observed differences.

In a study by Nelson et al. [9], the authors raise concerns that women undergoing DR may not receive all available information prior to mastectomy, as up to 41 % stated not having a discussion about advantages and disadvantages to reconstructive options, and 45 % would elect IR if given the option again.

Unfortunately, data regarding decision-making for DR are limited, and little is known about why women who initially express an interest in the procedure do not ultimately receive it. Additionally, most studies categorize women into having received a reconstruction or not, and do not differentiate between those who are awaiting the procedure from those who simply declined the procedure. Due to the fragmented nature of clinical databases in the USA, measuring national rates of post-mastectomy breast reconstruction is challenging. Our best estimates come from the Surveillance, Epidemiology, and End Results (SEER) database. However, this database only tracks reconstruction for up to 4 months post-mastectomy [10]. Any reconstruction performed later than 4 months is not recorded, which limits the ability to study delayed reconstruction, as the average time to DR following mastectomy is 2–4 years [2, 11].

The increased adoption of electronic health records following the Affordable Care Act holds promise for more comprehensive documentation regarding clinical decision-making. Specifically, information from electronic clinical documentation may provide further insight into patient education regarding options for breast reconstruction, as well as best practices for documenting such discussions [12–14].

The goals of this study thus were to explore the determinants impacting rates of delayed breast reconstruction, identify potential barriers to follow through with an initial decision to pursue delayed reconstruction, as well as to characterize the adequacy of the electronic health record to provide information pertaining to the decision-making process for breast reconstruction, and reveal potential opportunities for improved patient education and shared clinical decision-making.

## Methods

A retrospective cohort design was used to assess records of women undergoing mastectomy at a single academic medical

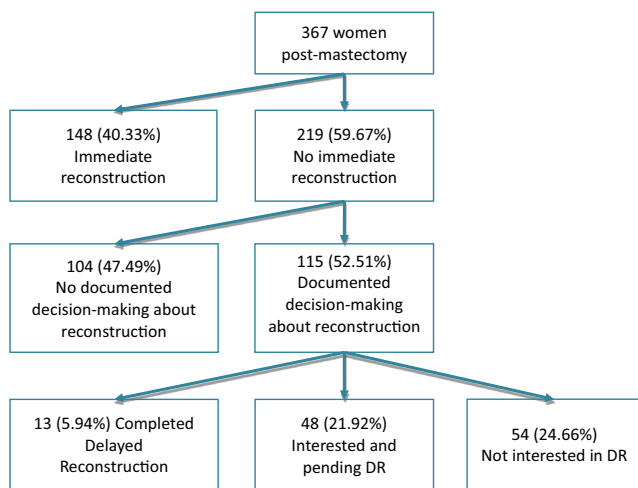
center, from 2008 to 2012. Appropriate IRB approval was obtained for the study. All women undergoing mastectomy were identified from the cancer registry using the International Classification of Diseases for Oncology (ICD-O3) and surgical CPT codes. The cohort included women who had either a unilateral or bilateral total mastectomy for in situ or invasive breast cancer, including women undergoing contralateral prophylactic mastectomy. Exclusion criteria included male breast cancer, women undergoing partial mastectomies, and women who had undergone a mastectomy for prophylactic reasons without a concurrent diagnosis of breast cancer.

Data collected consisted of patient demographics, post-mastectomy reconstruction status, timing between mastectomy and reconstruction, tumor stage, and co-morbidity index. Information regarding clinical decision-making was derived from an extensive review of the electronic medical records of all members of the multidisciplinary team including plastic surgeons and primary care providers. All preoperative and postoperative surgery notes as well as final pathology reports were reviewed. Reasons for not following through with DR, when available, were recorded and then classified into categories of: poor timing (e.g., scheduled trips, awaiting family member for social support, taking care of young children or ill family members), indecision (e.g., patient was unsure whether to pursue reconstruction, or unsure which method of reconstruction to choose), desired method of reconstruction not available at the treating institution, patient obesity, positive smoking status, and “undocumented reason.” A single clinician abstracted and categorized all data from the electronic medical records. The study period was determined based on data availability from the institutional EMR, which was implemented in 2008.

Descriptive statistics were used to report data pertaining to demographic and tumor stage. Women undergoing total mastectomy without immediate reconstruction who expressed an interest in delayed reconstruction were compared to women who declined reconstruction and to women who completed delayed reconstruction (Fig. 1). For comparisons across groups, a two-tailed *t* test was used for continuous data and chi squared for categorical data. A two-tailed Fisher’s exact test was used for marital status, and Mann-Whitney test for the Charlson’s co-morbidity index comparison.

## Results

From the year 2008 to 2012, a total of 367 women were identified undergoing total mastectomy for breast cancer (Fig. 1). One hundred forty-eight women (40.33 %) had IR, either with tissue expanders or autologous tissue. Out of the remaining 219 women, 13 (5.9 %) completed DR, 48 (21.9 %) expressed interest but were still pending reconstruction, 54



**Fig. 1** Retrospective 5-year study of 367 post-mastectomy women at one institution, and their decision regarding breast reconstruction

(24.6 %) expressed no interest in reconstruction, and 104 (47.5 %) did not have reconstruction and lacked any documentation regarding decision-making (Table 1). The median follow-up for women who were interested but still pending reconstruction was 2 years and 10 months, with a range of 10 to 69 months. The mean time interval between mastectomy and receipt of delayed reconstruction was 22 months, with a range of 8 months to 3.5 years.

Demographics of the 219 women who received total mastectomy without immediate reconstruction demonstrated a median age of 61 years (95 % CI of median 58–63) and median BMI of 26.60 (95 % CI of median 25.58–28.13). Within this cohort, 59.5 % were married/partnered versus 40.5 % who were single, divorced or widowed. Of 100.0 %, 52.6 % had never smoked, 37.7 % were ex-smokers, and 9.7 % were current smokers. The most common Charlson’s index was 5 (range 2–12), and the most commonly observed stage of breast cancer was stage I (29.6 %).

There were no statistically significant differences in any of the clinicopathologic variables assessed between women who completed DR and those who were still pending reconstruction (Table 2).

Of the 48 women who indicated an interest in reconstruction but were awaiting the procedure, the following reasons were identified explaining lack of follow through in delayed

reconstruction: poor timing (25 %), indecision (17 %), desired method of reconstruction not readily available at treating facility (10 %), persistent obesity (8.3 %), continued smoking (4 %), and undocumented (35 %) (Table 3).

A total of 53 women declined DR. Their age was significantly greater than women who were interested in DR (median 48.5 vs. 61.0,  $p < 0.001$ ), as was their Charlson’s index of co-morbidities (mode 3 (25 %) vs. 7 (22.6 %),  $p = 0.005$ ). Tumor stage was lower in women who declined DR (peak stage III 38.3 %) compared to those who expressed interest in DR (peak stage I 36.2 %). Marital status, median BMI, and smoking status were not significantly different between these two groups of women (Table 4).

Demographics of women who had documentation regarding the status of delayed reconstruction (i.e. completed DR, pending DR or declined DR) varied significantly compared to women who lacked documentation (Table 5) with respect to median age (51.5 vs. 68.0,  $p < 0.001$ ), predominant Charlson’s index score (3 (23.7 %) vs. 8 (21.2 %),  $p < 0.001$ ), and BMI (median 26.3 vs. 27.38,  $p = 0.05$ ). There were no significant differences in marital status or smoking history.

**Discussion**

Variation exists in the receipt of breast reconstruction following mastectomy. Our study demonstrated a 43.9 % rate of breast reconstruction, either at the time of mastectomy ( $n = 148$ , 40.33 %), or within 3.5 years of mastectomy ( $n = 13$ , 3.5 %). On average, women underwent delayed reconstruction 21.5 months after mastectomy (range between 8 months and 3.5 years). These findings are consistent with previous findings reported in the literature [2, 8]. Approximately 25 % of the women who were offered reconstruction in our study declined; thus demonstrating that reconstruction is not the ideal choice for all women undergoing mastectomy, and that following mastectomy rates as a quality metric without adjusting for patient choice may not provide adequate measurement data. However, clinicians need to be certain that the decision to decline reconstruction is truly informed based on appropriate patient education, as noted by Nelson et al [9].

**Table 1** Quantitative comparison of women with breast cancer who underwent mastectomy, and their status regarding DR, in a 5-year retrospective study

Years ( <i>n</i> patients)	2008 (64)	2009 (83)	2010 (65)	2011 (74)	2012 (81)	Total (367), %
Patients without IR	39	43	46	47	44	219
Had DR	4	3	2	4	0	13 (5.9)
Interested in DR	7	8	12	11	10	48 (21.9)
Declined DR	11	13	8	10	12	54 (24.7)
Lack of documentation	17	19	24	22	22	104 (47.5)

IR immediate reconstruction, DR delayed reconstruction

**Table 2** Comparison of characteristics of post-mastectomy women with breast cancer awaiting delayed reconstruction (DR) with those who already received DR. Five-year, retrospective study

Patient characteristics	Interested in DR ( <i>n</i> = 48)	Already had DR ( <i>n</i> = 13)	<i>p</i> value
Age, median (95 % CI of median)	48.5 (46.0–53.0)	46.0 (41.0–55.0)	0.331*
Cancer stage, mode (%)	III (38.3)	II (41.7)	n/a
Marital status, <i>n</i> (%)			1.000**
Single/divorced/widowed (%)	16 (34)	4 (31)	
Married/fiancé/partner (%)	31 (66)	9 (69)	
BMI, median (95 % CI of median)	25.7 (23.23–27.73)	28.15 (21.87–31.61)	0.888*
Smoking status, <i>n</i> (%) <sup>a</sup>			0.275***
Never smoked (%)	32 (67)	5 (42)	
Current smoker (%)	4 (8)	2 (17)	
Ex-smoker (%)	12 (25)	5 (42)	
Charlson’s index, mode (%)	3 (25.00)	3 (38.46)	0.917****

DR delayed reconstruction, CI confidence interval, n/a not available

\*unpaired *t* test for continuous variables, \*\*two-tailed Fisher’s test, \*\*\*chi squared test, \*\*\*\*Mann-Whitney test

<sup>a</sup> Percents may not add up due to rounding

We observed differences between women who declined DR versus those who were interested in DR. Women declining reconstruction were older, had higher cancer stages, as well as higher Charlson’s co-morbidity index scores. These findings are comparable to other studies in the literature [4, 10]; however, these studies did not specifically compare women who were *interested* in DR and those who *declined* it. Our study thus offers some additional insight to the current literature.

We found no statistical difference between women who completed DR and those who were still pending DR. This may in part be due to the small sample size of the women with delayed reconstruction. Further research may be required to determine if differences between these groups truly exist.

Although obesity was found as a documented reason for postponing reconstruction, body mass index did not

significantly differ between any of the groups we studied. This lack of significance may be due to the small sample size of our study; however, this finding has also been reported in other studies [2, 15].

Smoking is considered a relative contraindication to reconstructive surgery by some plastic surgeons, due to known increased risks of complications such as flap necrosis specifically related to breast reconstruction. In addition, smoking increases perioperative morbidities such as pneumonia, abdominal hernia, and thromboembolism [16]. However, we did not find smoking status to be a significant factor in whether or not DR was completed. Differences in perceptions of smoking risk, type of reconstruction (e.g., implant versus autologous), willingness to accept risk, underreporting of smoking status, and limited sample size are all potential explanations for this observation.

**Table 3** Documented reasons for lack of follow through in delayed reconstruction in women indicating interest (*n* = 49)

Needs to quit smoking	2	Physical	6 (12.5 %)
Needs to lose weight	4		
Timing: taking care of young children	3	Timing	12 (25 %)
Timing: trip	2		
Timing: time off from work	2		
Timing: wants to regain energy post op	1		
Timing: other (not specified)	2		
Needs more social support for TRAM	1		
Scheduled: waiting for OR	1		
Method of choice not offered locally: seeking second surgeon opinion out-of-state	3	Technical	5 (10.4 %)
Method of choice not offered locally: awaiting until available (large volume fat grafting)	2		
Disagreement between surgeon and patient	1	Disagreement	1 (2 %)
Still deciding (about reconstruction options, choice of surgeon or whether to have it at all)	8	Still deciding/unknown	25 (52 %)
Reason not specified	17		

One patient’s documented reason fell into two different categories

**Table 4** Comparison of characteristics of post-mastectomy women with breast cancer who indicated interest in delayed reconstruction (DR) with those who declined DR. Five-year, retrospective study

Patient characteristics	Interested in DR ( <i>n</i> = 48)	Declined DR ( <i>n</i> = 53)	<i>p</i> value
Age, median (95 % CI of median)	48.50 (46.00–53.00)	61.00 (54.00–65.00)	<0.001*
Cancer stage, mode (%)	III (38.29)	I (36.17)	n/a
Marital status, <i>n</i> (%)			0.537**
Single/divorced/widowed (%)	16 (34)	22 (42)	
Married/fiancé/partner (%)	31 (66)	31 (58)	
BMI, median (95 % CI of median)	25.70 (23.23–27.73)	26.63 (24.80–29.57)	0.867*
Smoking status, <i>n</i> (%) <sup>a</sup>			0.267***
Never smoked (%)	32 (67)	26 (51)	
Current smoker (%)	4 (8)	5 (10)	
Ex-smoker (%)	12 (25)	20 (40)	
Charlson's index, mode (%)	3 (25)	7 (22.64)	0.005****

DR delayed reconstruction, CI confidence interval, n/a not available

\*unpaired *t* test for continuous variables, \*\*two-tailed Fisher's test, \*\*\*chi squared test, \*\*\*\*Mann-Whitney test

<sup>a</sup> Percents may not add up due to rounding

Another important finding in this study was the large number of patients who lacked documentation concerning the decision-making process for breast reconstruction. Women who were lacking documented decision-making discussions with plastic surgeons differed from those who had documented decisions regarding delayed reconstruction (i.e., women who were either interested in DR, received DR, or declined DR). Women without documented discussions were, on average, older, had greater comorbid status, and higher BMI. Of course the lack of documentation does not necessarily mean that a discussion did not take place; however, the possible bias on the part of the physician toward not educating these patients about reconstructive options is raised. Providing fewer options to women perceived to be sicker, older, or with more advanced disease is not a new paradigm. Surgeons can be

selective in their discussion patterns, which in turn may strongly influence a woman's attitude toward reconstruction [17–19] and is an important consideration in any study of decision-making in breast reconstruction.

Given recent legislation in some states mandating a discussion of breast reconstruction options with patients receiving mastectomy, the high incidence of undocumented decision-making underscores an opportunity for improving attestation of patient education, shared decision-making, and informed consent.

Interestingly, among reasons for lack of follow through with DR, we did not identify any mention of patients' concerns about safety or future cancer surveillance post reconstruction. It may be that those concerns were alleviated during a discussion about breast reconstruction options, or that

**Table 5** Comparison of characteristics of post-mastectomy women with breast cancer who either indicated interest in delayed reconstruction (DR), declined DR, or had already received DR with those whose decision was undocumented. Five-year, retrospective study

Patient characteristics	Documented ( <i>n</i> = 115)	Undocumented ( <i>n</i> = 104)	<i>p</i> value
Age, median (95 % CI of median)	51.50 (49.00–55.00)	68.00 (65.00–70.00)	<0.0001*
Cancer stage, mode (%)	II (31.13)	I (34.0)	n/a
Marital status, <i>n</i> (%)			0.332**
Single/divorced/widowed (%)	42 (37.2)	45 (44.2)	
Married/fiancé/partner (%)	71 (62.8)	57 (55.9)	
BMI, median (95 % CI of median)	226.30 (25.10–27.73)	27.38 (25.60–29.18)	0.0501*
Smoking status, <i>n</i> (%) <sup>a</sup>			0.383***
Never smoked (%)	63 (56.1)	50 (48.1)	
Current smoker (%)	11 (9.9)	10 (9.6)	
Ex-smoker (%)	37 (33.3)	44 (42.3)	
Charlson's index, mode (%)	3 (23.68)	8 (21.15)	<0.001****

DR delayed reconstruction, CI confidence interval, n/a not available

\*unpaired *t* test for continuous variables, \*\*two-tailed Fisher's test, \*\*\*chi squared test, \*\*\*\*Mann-Whitney test

<sup>a</sup> Percents may not add up due to rounding

patients simply declined interest for other reasons. Prior studies revealed that women who had not received reconstruction demonstrated significant information needs related to reconstructive decision-making [2], although that finding was contradicted by another study in which the majority of subjects were satisfied with their decision-making process and information [8]. In our study, 17 % of subjects delayed reconstruction due to indecision, which included whether to undergo reconstruction at all and which type of reconstruction to choose. It is possible that these women would have benefited from additional educational tools and comprehensive clinical decision aids to assist the decision-making process [20]. It is therefore important to discuss with patients not only their interest in breast reconstruction but also any obstacles they may be experiencing in obtaining a desired reconstruction. For example, if barriers related to timing are present, it is essential to ensure that patients clearly understand that their decision for reconstruction can be revisited at any later date, as needed. A greater understanding of the barriers to delayed reconstruction may help clinicians tailor discussions to particular patient needs and provide information in more effective formats, thereby enhancing patient satisfaction and quality. Furthermore, with improved documentation, any unmet needs in patient education may be uncovered and remediated, if they do exist.

Finally, this study gives us the opportunity to educate clinicians in the importance of effective documentation, and brings to the fore possibilities in quality improvement. For instance, it may be beneficial to include a checklist in every patient chart to document the progress of referrals to plastic surgeons, and patients' decisions and possible barriers, so they may be addressed at the next visit. Or perhaps a pop-up may appear in the EHR, notifying clinicians of milestones they may have failed to document achieving in discussions with their patients. In such a manner, we may adequately gather more comprehensible data regarding the discussions between clinicians and their patients, and from there, study ways to improve patient education about post-mastectomy breast reconstruction. Achieving better patient-centered outcomes may be as much about educating the patients as educating the clinicians in opportunities to improve care.

## Limitations

Limitations of this study are recognized. The institutional EMR was implemented 5 years ago, and thus we limited our database to those 5 years; resulting in a relatively small sample size which may not allow the power to detect differences between subsets of our study population. None of the women who had a mastectomy in the last year of our database (2012) had a delayed reconstruction, as they were followed for less than 1 year, and may not have had enough time to undergo

reconstruction. We may thus be underestimating our rates of DR. It took up to 4 years in Morrow's study [21] for the number of women who had not undergone reconstruction to still consider the procedure to decrease to 11 %. The retrospective nature of the study also limits control of possible confounders and from knowing all of the details of the clinical decision-making process. Finally, the rather homogeneous nature of our patient population may limit the ability to generalize findings to more diverse ethnic populations.

## Conclusion

Some women do not receive breast reconstruction despite expressing an interest in the procedure. Reasons are multifactorial and consist of both patient- and provider-related factors. Documentation regarding decision-making for reconstruction is inconsistent. Our data highlight the two main decision points that patients face regarding reconstruction options: one at the time of initial surgery (IR versus other) or, for those who decline IR or are not a candidate, a subsequent decision for DR versus no reconstruction. The predictors of what drives each of these decisions may be different. The important implication may be that clinicians need to be more explicit about collecting patient preferences at each of these decision points. There is a need to focus our attention on women who express an interest in delayed reconstruction but do not receive it, in order to uncover any gaps in the patient education process or with shared decision-making which may create barriers to completing a desired choice of treatment. Our rates of delayed reconstruction are similar to reports in the literature. Further studies exploring barriers to reconstruction may have the potential to improve patient satisfaction following mastectomy.

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