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Understanding the factors that influence breast reconstruction decision making in Australian women

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Abstract:

Background: Breast reconstruction is safe and improves quality of life. Despite this, many women do not undergo breast reconstruction and the reasons for this are poorly understood. This study aims to identify the factors that influence a woman's decision whether or not to have breast reconstruction and to better understand their attitudes toward reconstruction. **Methodology:** An online survey was distributed to breast cancer patients from Breast Cancer Network Australia. Results were tabulated, described qualitatively and analyzed for significance using a multiple logistic regression model. **Results:** 501 mastectomy patients completed surveys, of which 62% had undergone breast reconstruction. Factors that positively influenced likelihood of reconstruction included lower age, bilateral mastectomy, access to private hospitals, decreased home/work responsibilities, increased level of home support and early discussion of reconstructive options. Most common reasons for avoiding reconstruction included "I don't feel the need" and "I don't want more surgery". The most commonly cited sources of reconstruction information came from the breast surgeon followed by the plastic surgeon then the breast cancer nurse and the most influential of these was the plastic surgeon. **Conclusions:** A model using factors easily obtained on clinical history can be used to understand likelihood of reconstruction. This knowledge may help identify barriers to reconstruction, ultimately improving the clinicians' ability to appropriately educate mastectomy patients and ensure effective decision making around breast reconstruction.

Keywords: mastectomy, breast reconstruction, barriers, decision making

Background

In Australia, 15000 women are diagnosed with breast cancer each year¹. Five year survival is now greater than 89% and breast reconstruction has not only been widely accepted as oncologically safe, but also shown to be beneficial to quality of life in women following mastectomy²⁻⁴. Clinical guidelines around the world recommend, and in many cases mandate, that breast reconstruction options be reviewed with every breast cancer patient. Despite these recommendations, even specialized cancer centres only reach reconstruction rates of 50-80%, while many national rates are as low as 5%⁵.

Several studies have identified demographic, tumour-related, hospital/geographic and psychological factors that influence the likelihood of reconstruction⁵. Despite this recent knowledge, the rates of reconstruction have been increasing at only a modest pace over the last 10 years⁶⁻⁸. With increasing availability and confidence of surgeons skilled in the spectrum of breast reconstructive options and the advances in implant materials, fewer contraindications exist and it is perhaps surprising that these rates are not increasing more rapidly.

In a recent Australian study⁴ it was shown that by offering all mastectomy patients reconstructive options during a multidisciplinary visit, the take up of breast reconstruction increased from the national average of 12% to an impressive 41%. This still leaves 59% of women choosing not to have reconstruction; many for reasons we have not yet identified.

Since the majority of women seeking breast reconstruction will likely be long-term survivors, the choices they make will have long lasting effects on their quality of life. It is, therefore, important that surgeons and patients alike are given the tools for relevant education to allow for informed and effective decision-making to occur. Recent studies have shown our success in this regard to be less than ideal⁹. In Australia, the National Safety and Quality Health Services Standards emphasize “Partnering with the consumer” to improve safety, quality and efficiency¹⁰. To date, however, published attempts to understand the patient’s experience around breast reconstruction in Australia have been minimal^{4,11-13}. This understanding can only be successfully achieved through patient-centered investigation into the factors that influence their decisions. As such, the purpose of this study was to report on the breast cancer reconstruction experience of a broad group of Australian women and describe the factors that influenced their decision whether or not to have breast reconstruction.

Subjects and Methods

The study population was derived from members of Breast Cancer Network Australia's (BCNA) Review and Survey Group, consisting of breast cancer survivors who agreed to be contacted for breast cancer research. Survey design and data collection was conducted by Cogentum Inc. (Melbourne, Australia) following qualitative research with breast cancer survivors, the BCNA and plastic and reconstructive surgeons. The purpose of this initial research was to inform the Neopec project, a multidisciplinary Victorian State government supported commercialisation project on breast reconstruction directed through the O'Brien Institute at St. Vincent's hospital in Melbourne. This data was de-identified and ethics review board approval was obtained for its analysis in this study.

The online survey was sent to all 1300 members of the database, of which 736 women responded (57%). We restricted our analysis to the 501 patients who had a complete mastectomy; either unilateral or bilateral (68% of respondents). The remainder, having undergone breast conserving surgery (BCS), were excluded. The survey was designed to gather details of the surgery performed as well as socio-demographic information. In addition, information regarding the patients' experience with breast cancer, such as timing of awareness of breast reconstruction options, information sources, influential individuals and reasons for choosing or not choosing breast reconstruction were also collected.

Statistical Analysis

The following variables were assessed for association with the probability of a patient opting for reconstruction: type of procedure (unilateral or bilateral mastectomy); type of hospital (public or private); location of hospital (urban or regional); age at surgery; family situation (children living at home or no children living at home); work status (employed or not employed); level of home/work responsibilities; level of home support; timing of discussion regarding reconstruction (discussion before surgery or no discussion before surgery) and influential individuals. Levels of home/work responsibilities and home support were measured on a 5-point scale, with high scores corresponding to higher levels of responsibility and support. Patients also used a 10-point scale to rate the degree to which individuals in their circle of care contributed to their decision.

Exploratory checks for collinearity were conducted on all variables and those identified to be important through uncontrolled logistic regression analyses were entered into a multiple logistic regression model. Model discrimination was assessed by calculating the area under the ROC curve, goodness-of-fit was assessed using the Nagelkerke pseudo- R^2 statistic, and the model was calibrated by means of the Hosmer-Lemeshow statistic. Diagnostic statistics for individual cases were also calculated.

To investigate the expected take-up rate of reconstruction among women who were not offered the option of reconstructive surgery, a subsidiary multiple logistic regression model was derived, excluding the factor relating to the timing of an offer of reconstruction, and applied to women who had received an offer of reconstruction. Parameter estimates obtained from this model were used to determine predicted probabilities of the expected outcome of reconstruction in women not offered the option of reconstructive surgery. The resulting proportion was then used to augment the overall estimate of the proportion of patients opting for reconstruction.

Results of exploratory analyses, diagnostic and calibration statistics and missing values analysis are given in an appendix to this document.

All data was analyzed using SPSS statistical software (Version 20.0).

Results

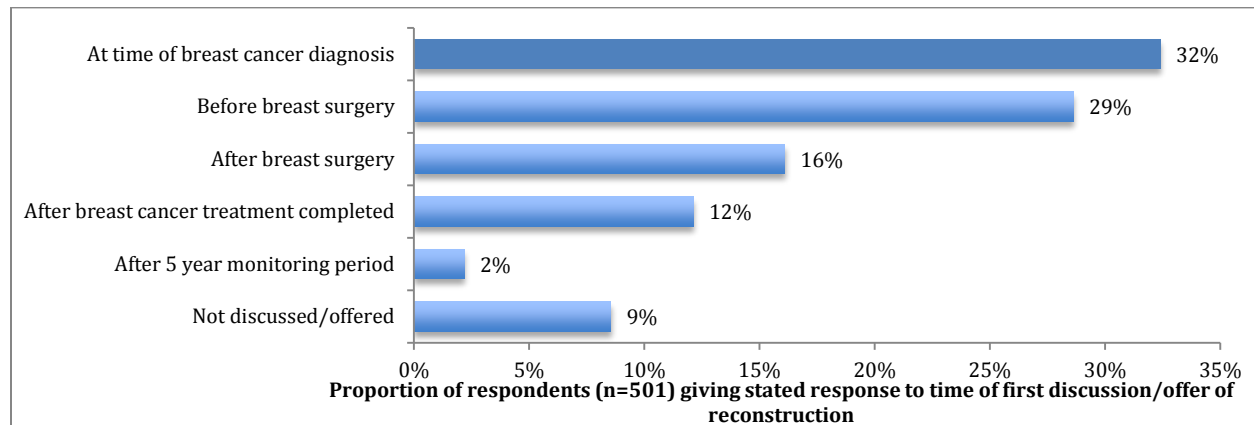
Sample Demographics

Of the 501 mastectomy patients included in the analysis, 323 (65%) had a unilateral mastectomy and 178 (35%) had bilateral mastectomies. 309 (61.5%) of these mastectomy patients underwent breast reconstruction; 140 (45%) had implant-based breast reconstruction, 135 (44%) had tissue transfer and 34 (11%) had both implant and tissue transfer. [Information as to the timing of the reconstruction was provided by 293 mastectomy patients who underwent breast reconstruction. Of these, 130 patients \(44.4%\) underwent immediate reconstruction while the remainder had a delayed reconstruction.](#)

Average age for the cohort was 48.9 years (standard deviation 9.1 years). 403 (80.4%) of our study patients were employed at the time of their breast surgery and 351 (70.1%) had access to private hospital cover. Most patients had children living at home (270; 53.9%) and had moderate to high home/work responsibilities (median score: 4 on a 5 point scale) and support at home (median score: 4 on a 5 point scale).

Almost all patients in this sample (91%) recall having had some discussion regarding reconstruction (9% never had the option of reconstruction discussed with them). 61% had their initial discussion prior to their breast surgery.

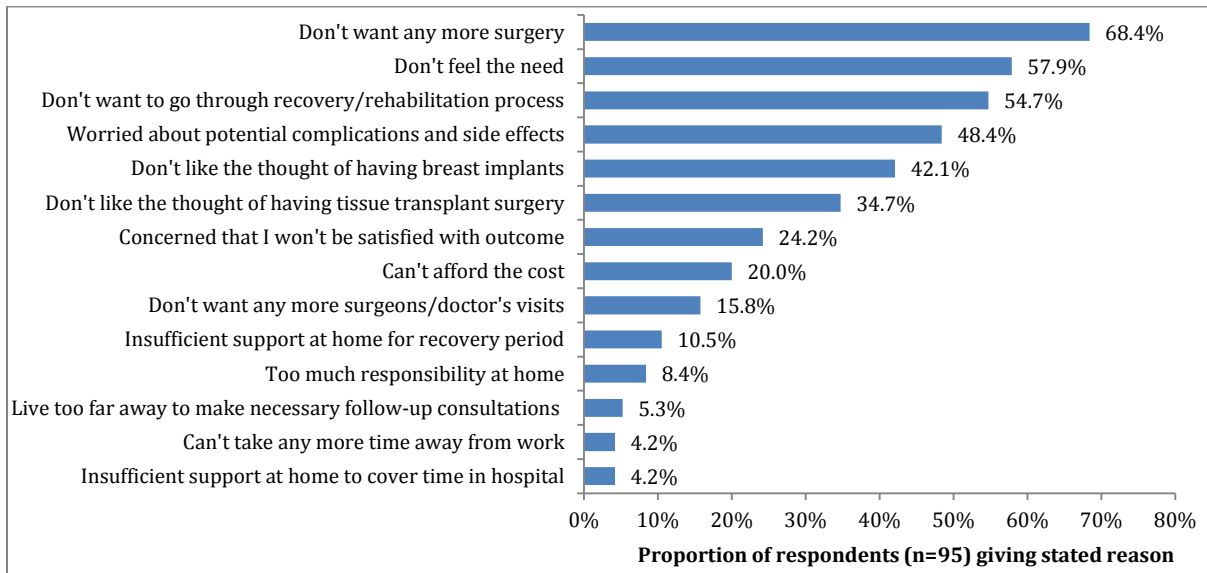
Figure 1: Timing of first discussion (n=501)



Reasons for choosing not to have breast reconstruction

Of the women who thought about and decided not to have breast reconstruction (n=95), the most common reasons for their decision included “I don’t want any more surgery” (68%) and “I don’t feel the need for it” (58%). These women were also significantly worried about the potential of future complications, additional hospital visits and poor outcomes. Notably, 20% of this group also said they “can’t afford the cost of the surgery”. Additional reasons recorded are described in Figure 21 below. These reasons were not different when unilateral and bilateral cases were compared ($P > 0.05$)

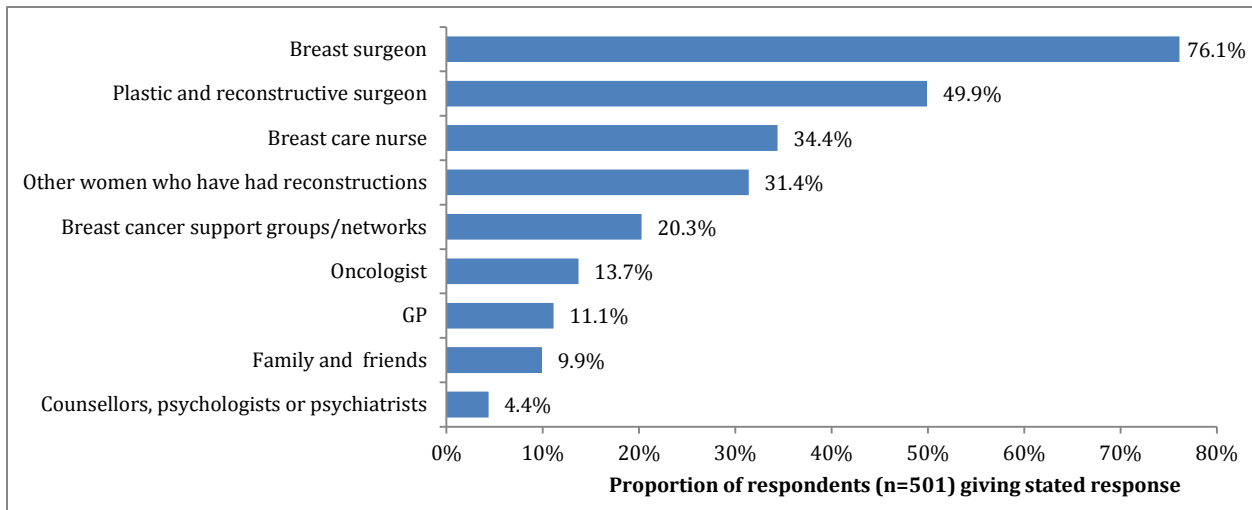
Figure 2: Patients' reasons for choosing not to have breast reconstruction surgery



Sources of information regarding reconstruction

The most commonly selected source of information regarding breast reconstruction came from the Breast Surgeon (76% selected), the Plastic & Reconstructive Surgeon (50% selected) and Breast Care Nurse (35% selected) (Figure 3).

Figure 3: Sources of awareness/information regarding breast reconstruction

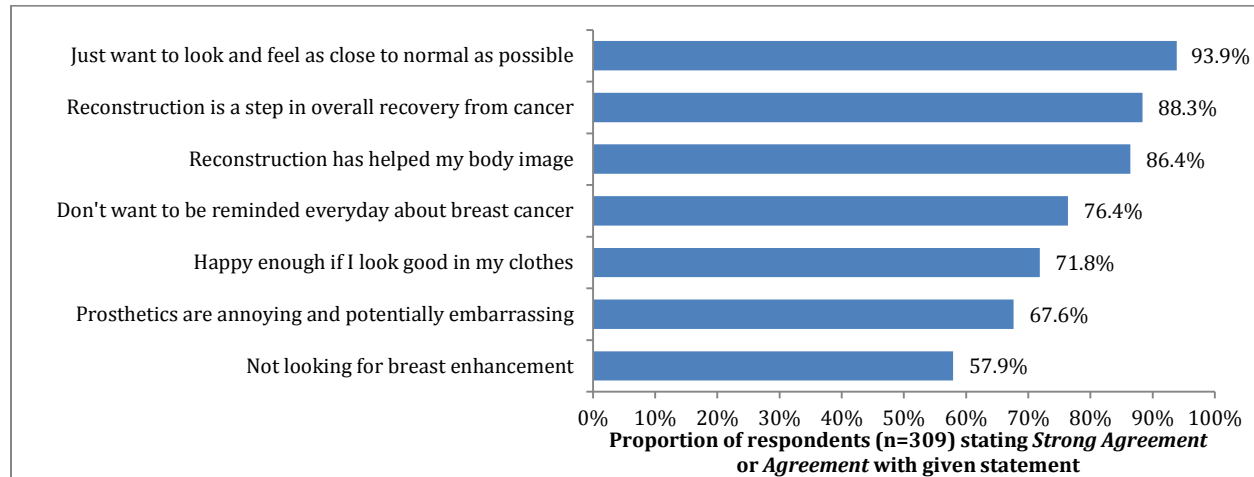


Similarly, when asked specifically who was most influential in helping to decide whether or not to have a reconstruction, the Plastic & Reconstructive Surgeon, the Breast Surgeon and other women who have had reconstruction were the top three stated responses.

Social and emotional reasons for reconstruction

Figure 4 describes the social and emotional reasons for having breast reconstruction. This group of reconstructed women most commonly “Agreed” or “Strongly agreed” that they “just want to look and feel as close to normal as possible” (94%); that “Breast reconstruction has been another step in my overall recovery from breast cancer” (88%); and that “Breast reconstruction has helped my body image” (86%).

Figure 4: Social and emotional reasons for having breast reconstruction (n=309)



Factors associated with reconstruction

Univariate logistic regression models found all considered variables, except some of the “influential individuals” to exhibit either a substantive effect or a statistically significant association with the outcome measure. These variables were then considered for inclusion in a corresponding multiple logistic regression model.

According to the multiple model, factors that positively influenced the likelihood of breast reconstruction included bilateral mastectomy ($p=0.001$), younger age ($p=0.046$), lower home/work responsibilities ($p=0.042$) and the influence of the plastic-reconstructive surgeon ($p<0.001$).

Variables that did not achieve statistical significance but showed some substantive importance included private hospital access ($p=0.058$), hospital location ($p=0.082$), early discussion of reconstructive options ($p=0.156$) and the influence of the breast care nurse ($p=0.111$).

Variables that were not associated with likelihood of reconstruction in a multiple model, and showed little or no substantive importance, included having children at home ($p=0.592$), employment status ($p=0.634$), increased level of support ($p=0.293$); the effect of the breast surgeon’s ($p=0.823$) or family and friends’ ($p=0.575$) reconstructive discussion.

Full descriptive statistics for all variables included in the multiple regression model, including descriptive statistics for all patients, and for the subset of patients who opted for reconstruction, together with p -values, odds ratios and associated 95% confidence intervals, are summarized in Table 1 below.

Table 1: Patient characteristic data comparing those who underwent reconstruction with those who did not.

Variable*	All patients (n=501)	Patients undergoing reconstruction (n=308)	p-value	OR	95% CI for OR
Mastectomy					
Unilateral	323 (64.5%)	181 (56.0%)			
Bilateral	178 (35.5%)	127 (71.3%)	0.001	2.50	(1.44, 4.32)
Hospital type					
Private	351 (70.1%)	228 (65.0%)			
Public	150 (29.9%)	80 (53.3%)	0.058	0.59	(0.34, 1.02)
Hospital location					
Regional	105 (21.0%)	54 (51.4%)			
Urban	396 (79.0%)	254 (64.1%)	0.082	1.70	(0.94, 3.08)
Family status					
No children living at home	231 (46.1%)	126 (54.5%)			
Children living at home	270 (53.9%)	182 (67.4%)	0.592	1.17	(0.66, 2.07)
Employment status					
Not employed full- or part-time	98 (19.6%)	54 (55.1%)			
Employed full- or part-time	403 (80.4%)	254 (63.0%)	0.634	1.17	(0.61, 2.27)
Timing of reconstruction discussion					
No discussion before surgery	195 (38.9%)	103 (52.8%)			
Discussion before surgery	306 (61.1%)	205 (67.0%)	0.156	1.44	(0.87, 2.40)
Age at surgery (years): mean (SD)	48.9 (9.1)	47.7 (9.0)	0.046	0.97	(0.94, 1.00)
Level of home/work responsibilities: median (IQR)	4 (3-5)	4 (3-5)	0.042	0.72	(0.53, 0.99)
Level of home support: median (IQR)	4 (3-5)	4 (4-5)	0.293	1.14	(0.89, 1.46)
Effect of breast surgeon: mean (SD)	6.51 (3.34)	6.92 (3.10)	0.823	1.01	(0.92, 1.11)
Effect of plastic/reconstructive surgeon: mean (SD)	7.21 (3.40)	8.10 (2.71)	<0.001	1.27	(1.16, 1.39)
Effect of breast care nurse: mean (SD)	4.70 (3.46)	4.82 (3.51)	0.111	0.93	(0.84, 1.02)
Effect of family & friends: mean (SD)	4.75 (3.17)	4.94 (3.07)	0.575	1.03	(0.94, 1.12)

*The first given category of each categorical variable represents the reference category

Influence of individuals/agencies on reconstruction decision

Our model considers the patients rating of each of the influential individuals and compares this to whether or not they had a reconstruction. The breast surgeon, plastic surgeon and other women who have had reconstruction were selected by the patients as the most influential individuals. 65% (147 of 227) of those who selected the breast surgeon as the most influential underwent breast reconstruction while 60% (54 of 90) of those who selected the breast care nurse underwent breast reconstruction. The plastic surgeon had the greatest influence toward reconstruction with 76% of those who selected the plastic surgeon undergoing reconstruction (214 of 283; $\chi^2_{(1)}=55.9$; $p<0.001$). Furthermore, only the plastic surgeon provided a unique substantive contribution to the outcome (in other words, if each patient was given advice from all the influential individuals, only the plastic surgeon would add significant influence toward reconstruction.)

Discussion

The focus of this study is to identify the factors that influence Australian women faced with the decision of whether or not to have breast reconstruction. These factors include, but are not limited to, attitudes towards breast reconstruction, socio-demographic characteristics, economics, psycho-social needs and the influence of key medical and support people.

This data was obtained through a patient-centered survey with the limitations inherent to survey methodology that have been well described in related literature¹⁴. [Although our survey population was taken from a national cancer volunteer organization, volunteer bias i.e. women who have a specific interest in reconstruction may be over-represented.](#) Survey methodology; however, was also imperative to the relevance of this data. Our goal, through partnering with the patient, was to describe the Australian breast cancer patient's experience from their perspective. [This preliminary study, done with a specific patient population in one country, is not meant to dichotomize patients based on variables measured but rather to identify those factors which should be considered in all patients and studied further in our individual populations.](#) Ultimately, this should lead to the development of strategies moving forward to empower women and their caregivers to make informed and effective decisions about breast reconstruction.

There are two questions to consider when looking at delivery of breast reconstruction: First, the number of patients who are being offered reconstruction; Second, the number of patients actually opting for reconstruction. The number of mastectomy patients who are offered breast reconstruction is poorly reported with great variability described in the literature⁵. While it may be appropriate not to offer reconstruction to all patients due to the characteristics of the patient or their disease, ideally the reasoning for this should be delicately explained to these patients. Breast cancer management guidelines in the United Kingdom as well as The United States of America recommend "immediate breast reconstruction be discussed with all patients who are being advised to have a mastectomy, and offer it except where significant comorbidity or the need for adjuvant therapy may preclude this option."¹⁵⁻¹⁷ In addition, shared decision making provides patients with more confidence in clinical decisions and leads to greater knowledge for patients who may opt for conservative treatment.^{18,19} In our sample, only 9% of patients do not recall having any such discussion, indicating good transference of this information. Our data also suggests that it is the breast surgeon and the plastic and reconstructive surgeon who take most of the responsibility for making women aware of reconstruction options. Specifically, positive influence toward reconstruction comes predominantly from the plastic surgeon, above the influence from other members of the multidisciplinary team.

The second question, related to the number of patients actually undergoing reconstruction, remains. In a review of the worldwide breast reconstruction literature, Brennan et al describes an overall variability in reconstruction rates from 4.9% - 81.2% with most studies demonstrating only a marginal increase over time⁵. This review of 28 studies showed an overall reconstruction rate of 17%. Factors found to be associated with higher likelihood of undergoing reconstruction included: patient factors such as young age, white race, private health insurance, higher education/income; tumour factors such as early stage and lack of need for radiation; hospital/geographic factors such as urban location, hospital type, breast cancer centre, private hospitals; psychological factors, such as desire to avoid a prosthesis, 'feel whole again' and a belief in the importance of sexuality and body image (conversely less likely to have reconstruction because of a desire to avoid further surgery, fear of complications and not being informed of reconstructive options).

The economics of breast reconstruction have also had a large impact on rates of reconstruction worldwide.^{20,21} Australia may be a model to study this influence given its dual public/private health care system. Indeed, the population in this study was more likely to undergo breast reconstruction if they had access to a private hospital.

Our model, which shows good predictive capability, found that all considered variables were significantly associated with the likelihood of having breast reconstruction, or indicate some substantive effect, except for employment status. Controlling for other factors and covariates in a multiple model, the odds of having reconstruction, at best estimate:

- Are 2.5 times higher in patients who had bilateral mastectomy than in patients who had a unilateral mastectomy
- Are 41% lower in patients who had their mastectomy in a public hospital than in patients who had their mastectomy in a private hospital (borderline statistically significant)
- Are 44% higher in patients who had a discussion about breast reconstruction before their mastectomy than in patients who did not have a discussion about breast reconstruction before their mastectomy
- Decrease by 3% for every year of increasing age
- Decrease by 28% for every point of increasing responsibility
- Increase by 27% for every point on the influence scale that the patient rates the plastic/reconstructive surgeon

Our study compared those women who had reconstruction versus those that did not. Women who never had a discussion regarding reconstruction, however, represent a third population of interest. In fact, understanding why this particular group was never given the option of reconstruction is of paramount importance. In our study some systematic differences between patients who had at least some discussion regarding reconstruction (n=458; 91.4%) and those who never had such a discussion (n=43; 8.6%) were observed. The mean age of those offered reconstructive options was significantly lower than those not offered reconstruction (49 years [SD 9 years] vs. 53 years [SD 10 years]). Additionally, hospital location and family status were significantly different between these two groups with a higher proportion of those offered reconstructive options having their mastectomy in an urban hospital and having children living at home.

There are several significant limitations to this study. First, we did not collect information about tumour status or other comorbidities; factors which, during even the most well-meaning consultation, may cause the surgeon to avoid a discussion of breast reconstruction. Indeed, this has recently been shown to be a significant factor in Australian patients⁴. Despite the increased use of radiotherapy, the concomitant advances in microvascular free tissue transfer, alloplastic materials and autologous fat grafting make it likely that the absolute contraindications for breast reconstruction will decrease, making it even more important that all women at least have a discussion about reconstruction. Second, we did not ask women if they declined immediate reconstruction because they were told that their cancer surgery would be delayed to allow for the coordination of the two surgical teams. This is a very real scenario that must be investigated further and dealt with by increased communication between the Breast Surgeons and Reconstructive Surgeons. Finally, in this study, we do not report on patient

[satisfaction with their decision; a factor that needs to be further studied to better understand decision making around breast reconstruction.](#)

Conclusion

This study surveyed a cohort of mastectomy patients to demonstrate that younger age, bilateral mastectomy, private hospital access, urban hospital access, decreased home/work responsibility and early discussion of reconstructive options positively influence the likelihood of having breast reconstruction. The influence of both the breast surgeon and the plastic surgeon on the patients' decision to have reconstruction is also demonstrated. Clearly, the first step to improving the proportion of women receiving breast cancer reconstruction is to understand the current situation and the factors that are currently at play in decision making related to reconstruction. In recent years, studies such as ours, have been adding knowledge to the body of literature on this topic but with little increase in the numbers of women receiving reconstruction. Gaining insight from the patient's perspective into the potential barriers and enablers with regards to breast reconstruction can inform clinicians of interventions they can utilize in working closer with these women to provide complete breast cancer care.

Statement of Conflict of Interest

The authors have no conflict of interest with the analysis or presentation of this data

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Ethics

Ethics review board approval was obtained for this study through the Research Ethics Department at The Australian Catholic University.

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Captions

Figure 1: *Timing of first discussion (n=501)*

Figure 2: *Patients' reasons for choosing not to have breast reconstruction surgery*

Figure 3: *Sources of awareness/information regarding breast reconstruction*

Figure 4: *Social and emotional reasons for having breast reconstruction (n=309)*

Table 1: Patient characteristic data comparing those who underwent reconstruction with those who did not.

APPENDIX – Additional Statistical Analyses

Screening process – summary of output from univariate models

The following table summarises the p-values, odds ratios and 95% confidence intervals for the uncontrolled models. These models were used as a screening process to identify suitable variables for inclusion in the multiple model (i.e. those showing some substantive importance), reported in the main body of the text.

Variable	p-value	OR	95% CI for OR
Procedure			
Unilateral (reference)			
Bilateral	0.001	1.95	(1.32, 2.89)
Hospital type			
Private (reference)			
Public	0.015	0.62	(0.42, 0.91)
Hospital location			
Regional (reference)			
Urban	0.018	1.69	(1.09, 2.61)
Family status			
No children living at home (reference)			
Children living at home	0.003	1.72	(1.20, 2.48)
Employment status			
Not employed full- or part-time (reference)			
Employed full- or part-time	0.149	1.39	(0.89, 2.17)
Timing of reconstruction discussion			
No discussion before surgery (reference)			
Discussion before surgery	0.002	1.81	(1.25, 2.62)
Age at surgery (years)	<0.001	0.96	(0.94, 0.98)
Level of home/work responsibilities	0.148	0.86	(0.70, 1.48)
Level of home support	0.018	1.24	(1.04, 1.48)
Effect of breast surgeon	<0.001	1.13	(1.07, 1.20)
Effect of plastic/reconstructive surgeon	<0.001	1.25	(1.17, 1.33)
Effect of breast care nurse	0.080	1.05	(0.99, 1.12)
Effect of friends and family	0.003	1.10	(1.03, 1.17)
Effect of GP	0.624	1.02	(0.95, 1.08)
Effect of oncologist	0.581	0.98	(0.93, 1.04)
Effect of counsellors/psychologists/psychiatrists	0.621	0.98	(0.91, 1.06)
Effect of breast cancer support groups/networks	0.860	1.01	(0.94, 1.07)
Effect of other women who had reconstruction	0.401	1.03	(0.97, 1.08)

Assessment of collinearity

Collinearity checks conducted on all variables included in the multiple regression model determined that no pairs of variables were excessively collinear; with no values of the variance inflation factor exceeding 1.75.

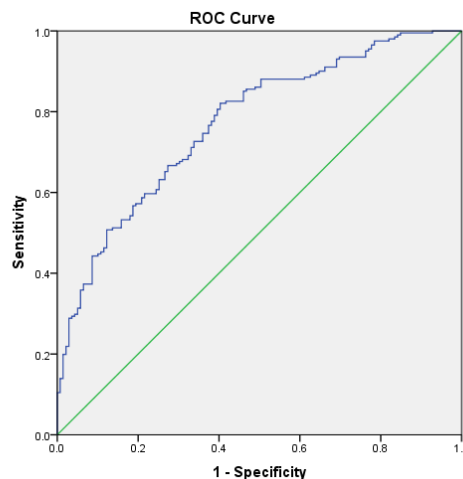
Model fit

The Nagelkerke pseudo- R^2 statistic for the multiple logistic regression model was found to be 28.3%; indicating that the model appears to be a good fit to the data; it does not seem likely that there are any “missing” variables which would explain a large proportion of the variance in the outcome.

Model discrimination

The ROC curve generated from predicted probabilities of the multiple model is shown in Figure 1 below. The area under the ROC curve was found to be 77.1% (95% confidence interval: 77.2 – 82.1%); indicating the model has good ability to distinguish between cases of reconstruction and no reconstruction. An optimum combination of sensitivity (80% approximately) and specificity (60% approximately) may be obtained using a cut-off value of 0.52 approximately. Using this value, 71.8% of cases were correctly classified.

Figure 1: ROC curve generated from model predicted probabilities



Model calibration and diagnostic statistics

The Hosmer and Lemeshow statistic was found to be non-significant ($\chi^2_{(8)}=13.3$; $p=0.103$); indicating that the model was adequately calibrated. No cases in the sample showed excessive leverage, with a maximum value of 0.12; within recognized tolerance limits. Furthermore, no cases appear to be excessively influential according to Cook's distance statistic, which did not exceed 0.41 in any case.

Missing data analysis

The multiple logistic regression model excluding timing of reconstruction decision and applied only to patients who had received an offer/discussion of reconstruction resulted in the following unstandardized parameter coefficients (variable categories as defined in main model):

Variable	Parameter coefficient
Mastectomy	0.881
Hospital type	-0.535
Hospital location	0.324
Family status	0.166
Employment status	0.162
Age at surgery (years)	-0.023
Level of home/work responsibilities	0.358
Level of home support	0.075
Effect of breast surgeon	0.051
Effect of plastic/reconstructive surgeon	-0.098
Effect of breast care nurse	0.233
Effect of family & friends	0.009
Constant	0.779