An evaluation of factors affecting preference for immediate, delayed or no breast reconstruction in women with high-risk breast cancer

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Abstract

Objective: Women with locally advanced breast cancer face many conflicting issues affecting their choice of immediate versus delayed versus no breast reconstruction (BR). This single-centre pilot study assessed high-risk women’s reasons and priorities in choosing the timing and type of BR in a setting where all clinically feasible options were discussed with all women.

Methods: Fifty-one women from a metropolitan breast oncology practice, who were likely to require post-mastectomy radiotherapy (PMRT), were recruited after making their decision about BR. Participants completed a questionnaire (69% preoperatively), adapted from Reaby (1998), evaluating the factors affecting their decision. Responses were subsequently classified into eight issue-based domains (feeling normal, feeling good, being practical, influence of others, expectations, fear, timing and unnecessary). Demographic and clinical data were also collected.

Results: There were 32 immediate BR (IBR = 63%), seven delayed BR (DBR = 13%) and 12 no BR (NBR = 23%). Analysis using the chi square test showed women over 60 were more likely to choose NBR (p = 0.005), while women living with a partner were more likely to choose IBR (p = 0.032). The most relevant domains for both IBR and DBR were ‘feeling good’ and ‘feeling normal’; and for NBR were ‘unnecessary’ and ‘being practical’. Although all women understood pre-operatively the potential aesthetic limitations of PMRT, 63% still chose IBR.

Conclusions: These data will enable clinicians, researchers and women with breast cancer to gain a clearer understanding of the factors that impact on the choice and timing of BR in women requiring PMRT, a major breast cancer survivorship decision.

Introduction

A systematic review of 28 original studies of both immediate and delayed breast reconstruction (BR) from seven countries found rates vary from 5–81% [1]. In most treatment centres, BR is only offered to a minority of women even though it is estimated that up to half may take up the option [1]. Rates of immediate BR (IBR) have recently been estimated at 13% for private patients and 6% for public patients in Australia [2], 21% for women in England [3] and 26% in the USA [4].

Previous research has shown that being given the option of BR has a positive impact on women with breast cancer [5,6]. These benefits include improved psychological well-being, quality of life, body image, vitality, femininity and sexuality [7]. Yet it remains unclear whether these benefits, often attributed to BR, are solely due to the outcomes of the surgical procedure itself or are at least partially due to control over the decision to have or not have BR [8,9].

The majority of research on quality of life and BR has focused on women’s satisfaction with outcomes, with fewer studies exploring women’s reasons for their choice. Those that have focused on reasons were limited by the fact that all but one were retrospective and that some participants (5% [10]; 27% [11]; 63% [12]) were not given the option of any BR, and therefore did not actually make a choice. In another study, none of the participants in the delayed BR (DBR) group were offered IBR [13], while the only other study to prospectively survey women was restricted to a cohort who had already decided to have BR [14]. There are no published prospective studies that report on women’s reasons for choosing to have or not have BR in settings where all women are offered a full range of reconstructive options.

One of the main reasons for surgeons not offering IBR is the anticipated need for post-mastectomy radiotherapy (PMRT) in women with large or node-positive breast cancers [1]. Planned PMRT is often considered a contraindication to IBR, both implant-based and autologous, due to concern about the potential for a higher rate of complications and inferior aesthetic results [15]. A meta-analysis of studies from

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1997–2009 concluded IBR with PMRT could be undertaken, although morbidity was higher [16].

Since 2009, there have been considerable advances in the practice of BR and delivery of PMRT. There is now evidence to support the oncological safety [17–19], acceptable rates of complications [19–22] and high levels of patient satisfaction with BR, even when the reconstruction is followed by PMRT [23–25]. It is timely to challenge previous views as the indications for PMRT are increasing [26], potentially further limiting the number of women being offered IBR.

This study is part of a larger ongoing project: the ‘Quality of Life after Immediate, Delayed or no BR (QoLID) study’, a prospective, longitudinal study covering a range of assessments including quality of life, pain, body image, decisional regret and aesthetic and clinical outcomes in women undergoing mastectomy and PMRT (ANZ Clinical Trials Registry Number 1261400045617). This sub-study is the first largely prospective study to focus on factors affecting the decision for BR in this group of women with high-risk locally advanced tumours where the need for PMRT was anticipated pre-operatively. It aims to document the reasons women with high-risk breast cancer choose IBR, DBR or no BR (NBR). In doing so, it will shed light on the role of choice in BR decision-making.

Patients and methods

Study setting and consent process

This single-site pilot sub-study took place in an oncoplastic breast surgical practice in metropolitan Sydney, Australia. It received ethics approval from the Human Research Ethics Committee at St Vincent’s Hospital, Sydney (13/059). Eligible patients interested in participating in the trial were referred to the trial coordinator. The coordinator explained the trial in detail and gave the patient a participant information sheet to read. Patients then had the opportunity to ask questions before either agreeing to participate and signing a written consent form, or declining to participate.

The trial was conducted in a cancer centre where all women with operable breast cancer undergoing mastectomy are offered IBR or DBR, with either implants or autologous tissue, or NBR. All women made this choice prior to enrolment in the trial. This decision requires women to balance their preferences for competing oncological, emotional and aesthetic issues. In the majority of cases, women’s reasons for their choice were documented prior to their mastectomy.

The initial discussion about mastectomy with or without BR occurred with an oncoplastic breast surgeon at the time of cancer diagnosis. In Australia, plastic surgeons are not permitted to perform mastectomies, and oncoplastic surgeons are not permitted to perform surgery involving vascular anastomosis (unless they are trained in these techniques). All three surgeons in this practice perform implant-based reconstruction, and one also does latissimus dorsi flaps. Women expressing an interest in autologous (tissue-based) free flap reconstruction were referred to a plastic surgeon to discuss this option more fully and determine their clinical eligibility for autologous reconstruction. Our oncoplastic surgeons work with six plastic surgeons across seven hospitals. If the patient is clinically eligible for, and chooses to have, autologous free flap BR (free TRAM or DIEP), the oncoplastic and plastic surgeons coordinate a time to do the procedure together.

Relative contraindications to any BR included a combination of patient factors (such as comorbidities and smoking), while specific contraindications for IBR included tumour factors (such as locally advanced and inflammatory breast cancer). In general, the plastic surgeons involved considered women likely to require PMRT ineligible for IBR with autologous tissue.

Eligibility and recruitment

Women eligible for the study were those needing mastectomy for invasive breast cancer and who were predicted to have a recommendation for PMRT based on the pre-operative tumour features. This included tumours estimated to be greater than 50 mm in diameter or having clinically involved lymph nodes. All women who satisfied these criteria were invited to participate. Women with inflammatory or metastatic breast cancer were ineligible. Participants were recruited from three oncoplastic breast surgeons between July 2013 and December 2014.

Questionnaire development

Reaby [11] documented women’s responses to published statements about their reasons for choosing to have or not have BR following mastectomy. Her study compared 64 women who wore external breast prostheses with 31 women who underwent implant-based BR between 1986 and 1992. The original statements used by Reaby were adapted in this study to produce a separate questionnaire for each of the three groups. These were named: reasons for immediate reconstruction; reasons for delayed reconstruction; and reasons for no reconstruction. Reaby’s original statements [see online Supporting information Appendix A] were not tested for reliability and validity [11]. Similarly, our adaptations of her questions for use in this pilot study of a high-risk cohort of women have not been previously tested.

The statements in each questionnaire were specifically tailored for each group, but some statements were common to all three groups. Participants were asked to select all statements (‘reasons’) that were relevant to their decision-making. The statements are provided in Figures 1–3. They were also given the opportunity to write an open response listing other reasons.
Domain development

Domains were developed by grouping similarly themed statements in the questionnaires. This process involved discussion among authors, and the final domains were based on pragmatic consensus views about what made most sense. Statements from the three questionnaires were grouped into a total of eight issue-based domains – not all appropriate for each group – to highlight the issues of most importance to women faced with this complex decision (Figures 1–3). The eight domains are: feeling normal, feeling good, being practical, influence of others, expectations, fear, timing and unnecessary.

For each statement, the number of ‘yes’ responses was totalled, and the average of these scores within each domain was calculated. Mean response rate (MRR) scores by domain are provided in brackets (next to the domain name) in Figures 1–3 as an indicator of the relative strengths of each domain.

Data analysis

Summary statistics were used to describe the demographic and cancer characteristics of the participants. Responses to the ‘reasons for reconstruction’ statements were cross-tabulated with the women’s age group and cohabitation.
status, using the chi square test. A *p*-value of less than 0.05 was considered to be statistically significant.

**Results**

Fifty-four eligible patients were invited, and three women declined. The reasons given were ‘not in the right head-space’; ‘not the kind of person who wanted to be reminded’; and ‘too busy.’ Fifty-one women consented to participate in the study with 35 (68.6%) completing questionnaires pre-operatively. One surgeon recruited 19 IBR, 0 DBR and eight NBR (*n* = 27) participants; one recruited 11 IBR, five DBR and three NBR (*n* = 19); and the third recruited two IBR, two DBR and one NBR (*n* = 5). Four women were assessed by the multidisciplinary team post-operatively as not requiring PMRT. However, their reasons for reconstruction data were still included in the analysis as they completed their questionnaires with the expectation that they would need PMRT.

Sixteen women (31%; six NBR and 10 IBR) did not complete their reasons for reconstruction questionnaires pre-operatively either because they were recruited post-operatively – due to the short time between making their decision and having surgery (*n* = 13) – or because they were too distracted to complete them prior to their operation (*n* = 3). The majority of these women (12 of 16) completed the questionnaire within 7 days of mastectomy (median: 5 days; range: 2–31 days). The one woman who took 31 days to return the form had been hospitalised post-reconstruction for an unrelated condition.

Table S1 [see online Supporting information Table S1] shows participant and cancer characteristics. In this relatively homogenous group, over 86% of participants from this largely Sydney-based population had private health insurance and they all shared high-risk disease characteristics. Table S2 [see online Supporting information Table S2] demonstrates that while the choice of NBR was correlated with older age, 47% of women aged over 60 still chose to have either IBR or DBR. Cohabitation status was also correlated with BR: 81% of women with a partner chose to have BR, with 73% of these women opting for IBR.

**Reasons for immediate reconstruction**

Within the IBR group, four women had bilateral synchronous cancer, and four had unilateral cancer but underwent...
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contralateral prophylactic mastectomy for the following reasons: two had BRCA gene mutations; one had a strong family history and a triple negative cancer; and one 71-year-old woman chose to have bilateral mastectomy and was subsequently found to have ductal carcinoma in situ in the contralateral breast.

Intermediate breast reconstruction consisted predominantly of two-stage reconstruction (n=27) with a tissue expander that was subsequently exchanged for a permanent prosthesis. Four women underwent ‘direct to implant’ single-stage reconstruction and one woman had a single-stage latissimus dorsi flap with implant.

Figure 1 shows the highest-scoring domains were feeling normal (MRR = 0.53) and feeling good (MRR = 0.63). Open responses were classified into the domains they were most closely aligned with (Figure 1) and support the important role of these domains in choice of BR.

**Reasons for delayed reconstruction**

Seven women chose to have DBR (including one woman who was not offered IBR due to oncological contraindications). Two women had prophylactic contralateral mastectomy to address asymmetry, and the remainder had unilateral mastectomies. Time since mastectomy ranged from 3 to 11 months (median time 8 months). As of July 2015, one woman had undergone a bilateral TRAM second-stage reconstruction (for unilateral cancer).

Figure 2 shows responses to 31 statements capturing both their reasons for wanting reconstruction and also for delaying reconstruction. The DBR group shared the same highest-scoring domains as the IBR group: feeling good (MRR = 0.54) and feeling normal (MRR = 0.54). Three women provided additional reasons for their choice.

**Reasons for no reconstruction**

Of the 12 women in this group, two had bilateral synchronous cancer, and one had a prophylactic contralateral mastectomy (BRCA2 mutation and history of ovarian cancer). The other nine had unilateral mastectomy.

Figure 3 shows the two highest-scoring domains for women declining BR were ‘unnecessary’ (MRR = 0.42) and ‘being practical’ (MRR = 0.21), with ‘fear’ of cancer recurrence, pain and complications of reconstruction also being relevant (MRR = 0.13). None of these women provided additional reasons for their choice.

**Discussion**

This cohort of high-risk women would not be offered IBR in many institutions because of concerns over potential adverse impacts of PMRT on aesthetic outcomes and the increased risk of capsular contracture [15]. Our unit policy has been to offer all women all options (in the absence of clinical contraindications). An audit of our practice showed a BR rate of 41%, over three times the national average, with no commensurate increase in adverse outcomes, providing evidence that expanding the indications for BR to women who were previously not considered eligible is a valid option [19]. These latest results support those findings, as all women were aware of the possible adverse cosmetic effects of PMRT prior to making their choice of reconstruction. Despite this information, 63% of our cohort chose IBR.

Our results demonstrated the range of reasons why women chose IBR, DBR and NBR. The majority of women who chose either timing of reconstruction prioritised the desire to feel normal and feel good. Conversely, the NBR group’s responses did not view BR as being essential to their physical or emotional well-being, and these women were more likely to be focused on becoming rid of the cancer and avoiding additional surgery. While the choice of NBR was correlated with older age, 47% of women aged over 60 still chose to have either IBR or DBR. Cohabitation status was also correlated with BR; however, 58% of women choosing NBR were also partnered, demonstrating that the choice of NBR was not restricted to older, non-partnered women [see online Supporting information Table S2].

**Utility of domains**

The results demonstrated the utility of grouping statements into issue-based domains. In the IBR and DBR groups, the same two domains were clearly the most important, with very similar numbers of responses for both groups of women. Responses to statements in other domains were still important to some, but not the majority of women, providing an indication of the variation in issues considered salient to choices about this complex decision.

The ‘expectations’ domain provided warning of the potentially unrealistic expectations some women have about BR, whereby they make their choice based on the possibility of BR making their life, not just their breasts, better than before. Whether these domain statements may have been interpreted by women as ‘compared with not having BR’ will be clarified in the revised reasons for choice of reconstruction questionnaires.

The ‘influence of others’ domain revealed deeper complexity surrounding decision-making roles. The influence of surgeons on a woman’s decision to have or not have BR has been widely recognised [1,14], but, not surprisingly, was not a major finding in this study, where all women were offered all options. Women who had chosen NBR did so for other reasons. No women in this group opted to provide additional reasons, which may have helped clarify these results. It may also indicate that the range of NBR statements was sufficient to cover all likely reasons,
possibly suggesting the decision for or against BR is more concrete than the choice between IBR and DBR.

Surgeons did appear to have more influence on the timing of BR. Seven women (23%) in the IBR group selected the statement ‘My surgeon strongly recommended this option’. The decision to have IBR was also influenced by women’s partners (16%) and recommendations from others (19%).

Results from the individual surgeons seemed to suggest variation in practice and influence. For example, although one surgeon appeared to influence women who wanted BR to have IBR (there were no DBR patients), only two of that surgeon’s 19 patients with BR selected the statement ‘My surgeon strongly recommended this option’.

Two women in the DBR group, one of whom had oncological contraindications for IBR, reported their surgeon as strongly recommending DBR, while another woman stated their surgeon was strongly against IBR. The small numbers within this group precludes any analysis of responses, although the additional comments from women highlighted their primary role in decision-making, reflecting their personal reasons for choosing DBR.

Limitations

The major limitations of these preliminary findings are the small sample size and the homogeneity of the study population. Ongoing research will provide a larger data set with a more heterogeneous population.

Another possible limitation was the necessarily subjective allocation of statements into domains. For example, we allocated the statement ‘I want to be able to wear many different types of clothing’ to the ‘being practical’ domain, but the ‘feeling normal’ or ‘feeling good’ domains were other options. Despite these classification issues, the addition of domains allows for a more meaningful analysis of the importance of related issues for women. The proposed additional statements for each of the revised questionnaires fit neatly into the current domains, giving some anecdotal support for their breadth and appropriateness.

Further research

This research project has highlighted potential improvements to the way data on women’s reasons for BR could be collected and assessed. The majority of research on quality of life outcomes following mastectomy has focused on assessing satisfaction with outcomes, and the impact this has on quality of life. However, rating satisfaction with reconstruction is not the same as understanding reasons for choosing reconstruction.

For example, current quality of life breast cancer questionnaires ask women to rate how satisfied they are with how they look when clothed, in a bra or swimming costume, or unclothed [27]. When focusing on reasons for choice of reconstruction, more appropriate questions to ask are how important it is to them to look good in these situations. The importance a woman places on these factors pre-operatively is likely to influence her choice of reconstruction. One study found objectively measured cosmetic results did not affect general quality of life, with self-perception of body image playing more of a role [28]. It will be informative to see if any correlations exist in women who place a high value on aesthetic outcomes and their choice of IBR or DBR, and autologous or implant-based final reconstruction, as another study has suggested [29].

The use of a Likert scale in future questionnaires will provide women with an opportunity to quantify the importance of each statement in determining their choice of BR (from very important to not important). It will also provide researchers and clinicians with a potentially deeper understanding of choice as participants will be asked to rate each statement. Ratings will allow for a standardised scoring system to be developed.

Participants’ open responses gave us an insight into other relevant additional statements that should be included, such as women wanting to feel normal for their children. Analysis of this pilot data also highlighted the absence of statements on preferences for implant versus tissue-based BR and the need for more specific statements about the choice of IBR (compared with BR generally). Finally, revised statements will include terms of reference to clarify comparators, so statements such as ‘BR will improve my quality of life’ will be amended to include ‘compared with not having BR’.

Conclusions

Asking women about their reasons for reconstruction pre-operatively in a setting of free choice can provide clinicians with information about women’s understanding of what BR can and cannot deliver. It also helps researchers to clarify to what extent patient satisfaction is due to the surgical outcomes of BR versus simply being given the opportunity to choose and provides baseline data for subsequent evaluation of the link between choice, outcomes and decisional regret. Finally, it is likely to help women to clarify in their own minds what is most important to them when weighing up the pros and cons of this complex cancer survivorship decision at a very stressful time.

For many women, aesthetic concerns may be of less importance than other issues, as our findings suggest: over 60% of women requiring PMRT still chose immediate implant-based reconstruction and some younger, partnered women still chose to have NBR. With increasing evidence of oncological safety [17–19], acceptable levels of complications [19–22], and high levels of satisfaction with IBR, even in the setting of PMRT [23–25], it is timely to revisit the surgeon’s
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primary role in BR decision-making and to fully discuss all options with all women.

Acknowledgements

The QoLID study is generously funded by The Friends of the Mater Foundation, North Sydney, Australia. The study sponsors did not influence the study design, collection, analysis or interpretation of data, or the writing of the manuscript. We also acknowledge Dr Cindy Mak’s contribution in recruiting patients to the study and Dr Linda Reaby for granting us permission to adapt her statements [11] for use in this pilot study.

Conflict of interest

All authors declare there are no conflicts of interest.

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Supporting information

Additional supporting information may be found in the online version of this article at the publisher’s web site.

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