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ORIGINAL ARTICLE

Understanding patient choices regarding breast reconstruction after mastectomy for breast cancer

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Abstract

Purpose In Australia, about 40% of patients undergo mastectomy to treat breast cancer, with negative impacts on body image, sexual function and quality of life. Whilst breast reconstruction is associated with increased patient self-esteem and a greater sense of wholeness and well-being, the national reconstruction rate is low at 18%.

This study aimed to compare demographics, treatment factors and information provision about breast reconstruction in women who had and did not have breast reconstruction following mastectomy treatment and identify goals and concerns underpinning women's reconstruction decisions.

Methods Female patients who had a mastectomy to treat breast cancer between 2010 and 2014 in a culturally and linguistically diverse (CALD) and socially disadvantaged region participated in a cross-sectional study, completing a questionnaire in their language of choice (English, Vietnamese, Chinese or Arabic).

Results Completed surveys were returned by 168 women (42% response rate; 77% English-speaking), of whom only 19.0% (n = 32) reported having had breast reconstruction. Reconstruction rates were significantly lower in women who reported speaking a language other than English at home versus only English (37.5% vs 62.5%, p = 0.03). However, all women expressed a desire for more information about breast reconstruction and more support to make their decision about breast reconstruction.

Conclusions Patients identified a need for greater information provision on breast reconstruction, highlighting an urgent need for resources specifically about breast reconstruction, particularly for non-English-speaking patients. Greater provision of information prior to mastectomy is critical to underpin breast cancer patients' decisions about breast reconstruction, especially for non-English speaking patients.

Keywords Breast cancer · Breast reconstruction · CALD · Mastectomy

Background

Breast cancer is the second most common cancer in the world, most common among women, with an estimated 1.67 million new cases diagnosed in 2012 worldwide (25% of all cancers) [1]. In Australia, breast cancer is estimated to be the most commonly diagnosed cancer in 2017 [2].

Breast cancer diagnosis and its treatment can be a difficult and stressful experience, impacting many aspects of a woman's life [3]. Patients may be confronted with physical and psychological changes, fear of death, anxieties about their body image, sexuality and self-esteem, concern for one's family and discomfort caused by treatment side-effects [4, 5].

In 2008, the peak national cancer organisation in Australia reported that about 40% of Australian women with breast

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cancer undergo mastectomy [6]. Mastectomy can have negative impacts on body image and sexual function and lead to poorer quality of life (QoL) outcomes [7]. New reconstruction techniques have broadened the options for patients undergoing mastectomy [8], which include immediate or delayed reconstruction using either autologous tissue or implants, with each option having its own set of advantages, disadvantages and risks [9]. Breast reconstruction after mastectomy is oncologically safe [10–12] and has been associated with high satisfaction, improved psychological, functional and sexual outcomes [13, 14], decreased anxieties about body image and sexuality, increased self-esteem and QoL and a greater sense of wholeness and well-being [15, 16].

Historically, breast reconstruction after mastectomy in Australia was reported to be as low as 5–6% [17], but this has increased to 18% with increased awareness and advancement in reconstruction techniques [18]. However, Australian rates remain lower in comparison to other countries. In the UK, immediate reconstruction rates alone were reported to be 23.3% in 2013–2014, hence the combined immediate and delayed reconstruction rate would be even higher [19]. In the USA, reconstruction rates range from 26 to 44%, with regional variations [20]. Similarly, in Australia, reconstruction rates vary by geographic area of residence, reported to be as high as 40% in a study in North Sydney, a more affluent geographic region [21].

The decision to undergo reconstruction is ideally based on consideration of the goal of the primary surgery and medical needs of cancer treatment such as radiation therapy, as well as the patient's personal preferences and physical characteristics [22]. Often women are making treatment decisions, including potentially having reconstruction, in a compressed time frame, when they typically experience a heightened level of emotional distress [23]. Accessing information about the benefits and risks of reconstruction is critical in facilitating women making an informed decision [24]. Decision quality has been defined as the extent to which treatment choice reflects the preferences of an informed patient. Therefore, a high-quality decision about reconstruction requires that patients have knowledge about reconstruction options, the treatment is consistent with their preferences and goals and they are as involved as they wish to be in making decisions about their care [25].

Uncertainty and perceived lack of information regarding reconstruction options, coupled with perceived lack of time to make decisions, are primary reasons for women not choosing reconstruction post-mastectomy [26, 27]. Typically, a discussion about mastectomy between patient and breast surgeon includes the option of reconstruction, occasionally followed by a consultation with a plastic surgeon [28, 29]. However, research continues to suggest that at times, these discussions do not occur and this variability in communication and lack of information exchange leave some patients with unmet information and support needs [24, 26, 27].

Previous research in women with breast cancer undergoing mastectomy has identified important barriers to pursuing or accessing reconstructive breast surgery, such as patient's age, race, income/socio-economic status, private health insurance status, stage of disease, lack of referral or information and cultural disparities such as limited English proficiency [30–33].

South West Sydney Local Health District (SWSLHD) is a culturally diverse region of Australia, with around 36% of the population born overseas and about 48% of the population speaking a language other than English at home. SWSLHD encompasses 14 of the 20 most disadvantaged suburbs in Sydney contributing to social determinants of health within the district [34]. The reconstruction rate in this area is 8.9% (unpublished data from Clinical Information of the 5 hospitals within South Western Sydney), but the reasons for this relatively low reconstruction uptake are unclear.

Currently, there are no data available in Australia about the rates of reconstruction in patients with culturally and linguistically diverse (CALD) backgrounds. In the USA, studies have compared reconstruction rates among different ethnic groups. One study of whites, African Americans, highly acculturated Latinas and less acculturated Latinas reported reconstruction rates of 40.9%, 33.5%, 41.2% and 13.5% respectively, which was thought to be related to limited information about reconstruction as well as limited access to plastic surgeons [35, 36]. Another study from the USA found that of 485 patients undergoing mastectomy, 41.6% underwent reconstruction (24.8% immediate and 16.8% delayed), with race being one of the factors associated with lack of reconstruction after mastectomy, and barriers reported as more common among non-white participants [37].

The primary purpose of this study is to compare women with breast cancer, in a socially disadvantaged area, who did and did not have reconstruction after mastectomy, in terms of demographics, treatment factors and provision of information about reconstruction. The second purpose is to identify the goals and concerns that informed women's decisions about reconstruction after mastectomy, specifically to identify barriers and facilitators to breast reconstruction. A further objective was to explore any differences in reasons for having or not having reconstruction between patients whose preferred language is Arabic, Chinese or Vietnamese versus English.

Methods

Setting

This cross-sectional study was undertaken at three hospitals performing breast cancer surgeries in SWSLHD, with ethical approval from the SWSLHD Human Research and Ethics Committee (HE15/093) and in accordance with the ethical

standards laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

Participants

Patients were eligible to participate if they (a) had a confirmed diagnosis of breast cancer, (b) had a mastectomy between 2010 and 2014, (c) had their operation at one of the three major metropolitan hospitals performing breast cancer surgeries in SWSLHD and (d) were female. Male breast cancer patients were not eligible to participate.

Measures

The survey instrument, specifically developed for this study, comprised 37 items, three of which requested free text responses/comments. The survey included 17 questions about demographics, encompassing age, age at time of mastectomy, educational level, race/ethnicity, language spoken at home, marital status, income and employment status and health habits; three about the patient's cancer treatment, covering the year and the hospital where mastectomy was performed and any adjuvant therapy received; seven about reconstruction decision-making, discussions of reconstruction, timing of these discussions and sources of information provision regarding reconstruction; and a section for the participants' comments in free text about reasons for having or not having reconstruction, factors that informed their decisions about reconstruction, and what support if any, would have been useful to help inform their decision about reconstruction.

Procedures

Each patient was sent a letter of invitation from her treating surgeon, the Patient Information Statement, questionnaire and a reply-paid envelope; and all documents were translated into Vietnamese, Chinese or Arabic. These languages were chosen as they comprised the largest groups of CALD patients in SWSLHD. Patients whose medical records noted that their first language was Vietnamese, Chinese or Arabic were sent study documents in both their respective language and in English. All other patients were sent the questionnaire in English. Hereafter, patients who returned their questionnaire in Arabic, Chinese or Vietnamese are referred to as the non-English-speaking group and those who returned their questionnaire in English as the English-speaking group. For patients who did not return a survey (either completed, implying consent, or not completed, implying non-consent), follow-up questionnaires were sent out 4 weeks and 8 weeks after initial mail-out; and at 12 weeks, a bi-lingual research assistant contacted remaining patients via telephone to determine their interest in participating and offering the option of completing the questionnaire by telephone in their preferred language (English, Vietnamese, Chinese or Arabic) with the bi-lingual research assistant.

Statistical analysis

Statistical analysis was performed with SPSS version 24. Categorical data, both dichotomous and non dichotomous, were analysed using Fisher's exact test. Continuous data were analysed with *t* test.

Results

Study participants

A total of 168 completed surveys were returned (42% of 398 surveys sent), of which 130 (77%) were in English (Fig. 1). As indicated in Table 1, the mean age of women at the time of their mastectomy was 55.8 (range 26–88) years (mean current age 60.3 years, range 29–92). The majority of patients were currently married or in a relationship ($n = 106$, 63.1%) and had children ($n = 145$, 86.3%). Our sample was well spread across all levels of education from those without a school certificate to those with a university degree and higher. Less than a quarter of the sample ($n = 41$, 24.4%) were in paid employment, and 57.1% ($n = 96$) held concession cards (pension cards $n = 68$, 70.8%). The majority of our sample was born overseas ($n = 110$, 65.5%) with Asia being the most common place of birth ($n = 51$, 46.4%). Over half of the sample ($n = 93$, 55.4%) spoke a language other than English at home.

Only 19.0% ($n = 32$) of the women who returned a completed questionnaire had a mastectomy and reconstruction. This included a small sample of the Vietnamese and Arabic-speaking women, but none of the Chinese-speaking women (Fig. 1).

As indicated in Table 1, 32 (19.0%) patients in the study population had reconstruction after mastectomy. Compared to women who did not have a reconstruction ($n = 136$, 81.0%), women who had reconstruction ($n = 32$, 19.0%) were significantly younger (mean age at time of mastectomy 45 vs 58 years), significantly more likely to be married ($n = 24$, 75.0% vs $n = 82$, 60.3%), have tertiary education ($n = 15$, 46.9% vs $n = 35$, 25.7%), be in paid employment ($n = 16$, 50.0% vs $n = 25$, 18.4%), earn more than AUD$1000 per week ($n = 9$, 28.1% vs $n = 12$, 8.8%) and to be born in Australia ($n = 15$, 46.9% vs $n = 43$, 31.6%); and significantly less likely to speak a language other than English at home ($n = 12$, 37.5% vs $n = 81$, 59.6%). Patients who had and did not have reconstruction were similar in terms of their rates of exercising, presence of comorbidities and receipt of adjuvant treatment (Table 2).

The majority ($n = 20$, 62.5%) of the patients who had a reconstruction had delayed and autologous ($n = 25$, 78.1%)

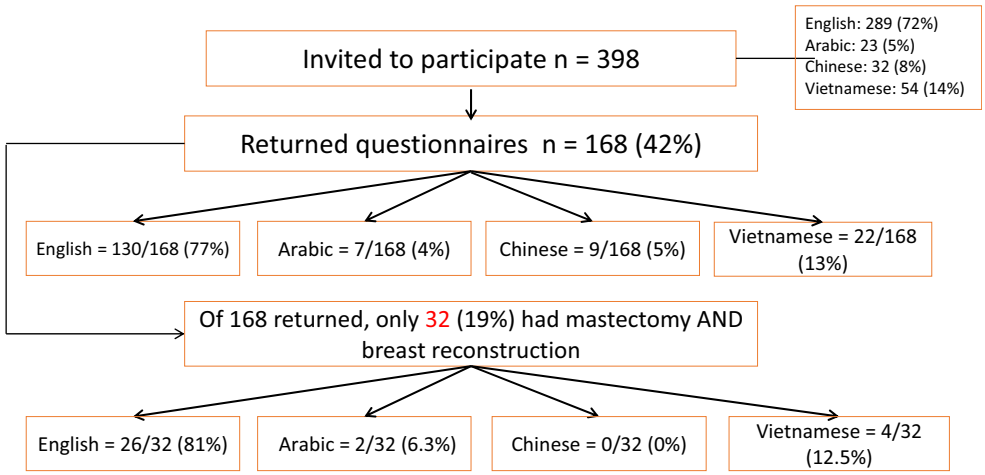

Fig. 1 Flow chart of study recruitment and participation

reconstruction in a public hospital ($n = 25$, 78.1%). Patients having a delayed reconstruction in a public hospital experienced an average of 9.3 months waiting time for this procedure.

The majority of our study population did not have reconstruction ($n = 136$, 81.0%) and over half of the patients did not even consider the option of a reconstruction ($n = 106$, 63.1%). Sixty-one patients (36.3%) said they considered reconstruction and about half of them went on to have one. More than half of our sample reported that they would not have a reconstruction if they were to have their mastectomy again ($n = 104$, 61.9%).

Table 1 Demographic information for participants including those who did and did not have breast reconstruction

		All patients ($N = 168$)	Patients who did not have a reconstruction($N = 136$, 81%)	Patients who had a reconstruction ($N = 32$, 19%)	p value
Age		60.3 (29–92)	63 ± 12.5	49 ± 9.9	p<0.001 t=-5.776 df = 165
Age at mastectomy		55.8 (26–88)	58 ± 12.3	45 ± 10.3	$p < 0.001$ $t = -5.587$ df = 165
Relationship status	Married/de facto	106 (63.1%)	82 (60.3%)	24 (75.0%)	$p = 0.162$
	Single/divorced/separated	61 (36.3%)	53 (39.0%)	8 (25.0%)	
Children	Yes	145 (86.3%)	118 (86.8%)	27 (84.4%)	$p = 0.807$
Education	Post-high school (trade/apprenticeship, certificate/diploma, university degree or higher)	50 (29.8%)	35 (25.7%)	15 (46.9%)	$p = 0.139$
	Finished high school or less	117 (69.6%)	100 (73.5%)	17 (53.1%)	
Employment	Employed (full-time, part-time, casual, on leave)	41 (24.4%)	25 (18.4%)	16 (50.0%)	$p < 0.001$
	Other (including pensioner and household duties)	108 (64.3%)	97 (71.3%)	11 (34.4%)	
Income	≤ $1000/week	103 (61.3%)	85 (62.5%)	18 (56.3%)	$p = 0.028$
	> $1000/week	21 (12.5%)	12 (8.8%)	9 (28.1%)	
	Prefer not to answer	44 (26.2%)	39 (28.7%)	5 (15.6%)	
Country of birth	Australia	58 (34.5%)	43 (31.6%)	15 (46.9%)	$p = 0.200$
	Other	110 (65.5%)	93 (68.4%)	17 (53.1%)	
Speak language other than English	Yes	93 (55.4%)	81 (59.6%)	12 (37.5%)	$p = 0.03$

Table 2 Comparison of health status and treatment between patients who did and did not have breast reconstruction

		All patients ($N = 168$)*	Patients who did not have reconstruction ($N = 136$, 81%)	Patients who had reconstruction ($N = 32$, 19%)	p value
Exercise—any exercise performed each week	Yes	137 (81.5%)	108 (79.4%)	29 (90.6%)	$p = 0.700$
Presence of any comorbidities	Yes	137 (81.5%)	115 (84.6%)	22 (68.8%)	$p = 0.157$
Adjuvant therapy	Yes	137 (81.5%)	110 (80.9%)	27 (84.4%)	$p = 1.000$
Radiotherapy	Yes	86 (51.2%)	67 (49.3%)	19 (59.4%)	$p = 0.537$
Chemotherapy	Yes	100 (59.5%)	77 (56.6%)	23 (71.9%)	$p = 0.27$

*Percentages are calculated using the full sample of 168 was used as the denominator, as each variable has some missing data

Timing of discussion and provision of information about breast reconstruction

As indicated in Table 3, two thirds of patients ($n = 21$, 65.6%) who had reconstruction had discussion about reconstruction prior to their mastectomy. This is in contrast to the patients who did not have reconstruction where almost half of them ($n = 58$, 42.6%) did not have reconstruction discussed with them. Only 28.7% ($n = 39$) of these patients had reconstruction discussed with them prior to their mastectomy. Almost a quarter of patients ($n = 7$, 21.9%) with reconstruction raised the issue themselves. The main source of information about reconstruction for these patients was the surgeon ($n = 27$, 84.4%). Almost a fifth of these patients ($n = 6$; 18.8%) however obtained information from the Internet.

Reasons for having or not having breast reconstruction

Most patients who had reconstruction ($n = 27$, 84.4%) cited their main reason for doing so was the need to feel as close to normal as possible. Of the patients who did not have reconstruction ($n = 136$, 81%), the most common reasons given were worry about potential complications and side effects

Table 3 Information provision regarding reconstruction for all participants, and for those who did and did not have breast reconstruction

		All patients ($N = 168$)	Patients who did not have reconstruction($N = 136$, 81%)	Patients who had reconstruction ($N = 32$, 19%	p value
Timing of reconstruction discussion	Never	58 (34.5%)	58 (42.6%)		$p < 0.001$
	Before mx	60 (35.7%)	39 (28.7%)	21 (65.6%)	
	After mx	37 (22.0%)	30 (22.1%)	7 (21.9%)	
Who raised reconstruction	Self	20 (11.9%)	13 (9.6%)	7 (21.9%)	$p < 0.001$
	Surgeon	62 (36.9%)	46 (33.8%)	16 (50.0%)	
	Nurse	6 (3.6%)	6 (4.4%)		
	Other	23 (13.7%)	15 (11.0%)	8 (25.0%)	
Would have reconstruction again	Yes	60 (35.7%)	37 (27.2%)	23 (71.9%)	$p = 0.001$
Source of information on reconstruction	Breast surgeon	80 (47.6%)	53 (39.0%)	27 (84.4%)	$p < 0.001$
	Plastic surgeon	29 (17.3%)	7 (5.1%)	22 (68.8%)	$p < 0.001$
	General practitioner	14 (8.3%)	10 (7.4%)	4 (12.5%)	$p = 0.691$
	Nurse	13 (7.7%)	10 (7.4%)	3 (9.4%)	$p = 0.833$
	Women who have had reconstruction	17 (10.1%)	14 (10.3%)	3 (9.4%)	$p = 1.000$
	Relative	7 (4.2%)	6 (4.4%)	1 (3.1%)	$p = 1.000$
	Friends	12 (7.1%)	11 (8.1%)	1 (3.1%)	$p = 0.680$
	Internet	22 (13.1%)	16 (11.8%)	6 (18.8%)	$p = 0.655$
	BCNA	24 (14.3%)	20 (14.7%)	4 (12.5%)	$p = 1.000$
	No information	54 (32.1%)	53 (39.0%)	1 (3.1%)	$p < 0.001$

mx mastectomy, *BCNA* Breast Cancer Network Australia consumer organisation

($n = 57$, 41.9%) and not having an interest in reconstruction ($n = 56$, 41.2%). The most commonly reported factors for women deciding to have reconstruction included younger age, no need to wear external prosthesis, need to feel better about oneself and provision of more information about reconstruction. When asked what would have been helpful in deciding about reconstruction, patients overwhelmingly cited the need for more information on reconstruction.

Of the patients who had reconstruction, the majority ($n = 23$, 72%) reported that they would have reconstruction again, should they have another mastectomy. Similarly, the majority of patients who did not have reconstruction ($n = 94$, 70%) also stated that they would not have reconstruction were they to have another mastectomy. Of note, a similar proportion of patients in each group (27–28%) indicated that they would choose the opposite action if given another chance i.e. 28% of patients who had reconstruction would not have it again, and 27% of patients who did not have reconstruction would choose to have it if given another chance.

Free text comments provided at the end of the survey suggested that patients who had reconstruction felt they had improved psychological wellbeing and QoL: "Extremely happy with the reconstruction and would highly recommend", "Very happy with the result of the breast reconstruction", "Now I look and feel the same as before". A number of the patients who did not have reconstruction expressed that they were not interested in it, particularly because of their age. Many of the patients, particularly the non-English-speaking patients, cited a lack of information about reconstruction as a factor for not considering or having reconstruction post mastectomy: "After breast cancer treatment completed, if I get more information about breast reconstruction and consultation from doctors, I am willing to do it"; "If I was given the information regarding the possibility of having immediate reconstruction prior to surgery"; "I may consider having breast reconstruction if I was given more detailed information and discussion about the procedure". When asked what would make the patients consider a reconstruction, the English-speaking patients seemed to focus on issues such as confidence, appearance and age: "I would do the breast reconstruction just because I want to feel better and more confident about my appearance and If I had been younger I may have considered reconstruction".

English-speaking versus non-English-speaking groups

Of the participants who returned the questionnaires, a small proportion (22.6%) were of the three language groups included in this study. The data suggests a pattern of non-English-speaking patients both receiving and seeking less information about reconstruction. For all patients, the surgeon was the most prevalent source of information on reconstruction, but non-English-speaking participants were half as likely to report having had discussions regarding reconstruction prior to their mastectomy and also half as likely to have raised the topic of reconstruction with their surgeon when compared to English-speaking participants. Non-English-speaking patients were also overall less likely to seek information about reconstruction, with almost half of the non-English-speaking patients ($n = 18$, 47.4%) compared to only 27.7% ($n = 36$) of English-speaking patients reporting that they did not seek any information on reconstruction. In addition, whilst 16.9% ($n = 22$) of English-speaking participants sought information on reconstruction from the Internet, none of the non-English-speaking patients did.

Discussion

In this cross-sectional study, we sought to understand patients' choices on breast reconstruction after mastectomy for breast cancer treatment, particularly in the non-English-speaking population. The survey return rate was low at 42% overall (45% of English-speaking and 35% of non-English-speaking patients), and the majority of respondents (77.4%) were English-speaking. As was representative of the population in the region, the majority of patients were born overseas and spoke a language other than English at home.

Only 32 of the questionnaire responders (19.0%) had had reconstruction after mastectomy, of whom six (18.8%) were of non-English-speaking background. Comparison of the patients who had and did not have reconstruction after mastectomy revealed that the patients who had reconstruction were younger, more educated, had higher income, were more likely to exercise and had fewer comorbidities, indicating that younger and healthier patients with financial means were more likely to undergo reconstruction, as reported in other studies [26, 38]. We also found that of the patients who did not have reconstruction, nearly half (43%) did not have reconstruction discussed with them at all and over a quarter (28.7%) did not have it discussed with them in the pre-operative setting. It is possible that clinicians made a judgement that the patient may not be suitable for reconstruction and therefore did not inform the patient about it despite guidelines which recommend discussing reconstruction with patients having mastectomy [28].

A survey of 296 patients (48% participation rate) with breast cancer who had a mastectomy found that patients who underwent reconstruction (55% of sample) were younger and had a higher satisfaction rate with their breasts, psychological and sexual well-being [39]. A larger survey of 638 patients 5 years after mastectomy for breast cancer (60% response rate) reported an overall reconstruction rate of 47% with 36% having immediate reconstruction and 11% delayed reconstruction. Patients who did not have reconstruction tended to be older, African American and in the lower income group, and

they also had higher unmet informational needs [26]. In Australia, a survey of 366 women who had mastectomy to treat breast cancer reported that patients who had reconstruction (25% of sample) were younger, more educated and had private health insurance [38]. The findings from these studies are similar to those from our study.

The majority of patients who did or did not have reconstruction indicated that they would choose the same option again if given a second chance. However, slightly over a quarter of patients who had reconstruction would not choose to have it again and those who did not have reconstruction would choose to have it if given the choice a second time. By far, the most common unsolicited comment from respondents was the need for more information about reconstruction, which is known to ultimately contribute to greater patient satisfaction with their choices and reduce the likelihood of decisional regret [40].

Low response rate is a study weakness and in retrospect, it may have been prudent to reduce the interval for subsequent questionnaires mail-outs to 2-weekly instead of 4-weekly. However, in addition to re-mailing the surveys, we implemented other strategies to increase participation rate. We mailed a teabag and a pen with the questionnaire to encourage patients to complete the questionnaire whilst having a cup of tea, increasing the response rate by 9%. Subsequently, bilingual research assistants telephoned women to offer assistance to complete the questionnaire over the phone, increasing the response rate by a further 12%. We highly recommend incorporating these as core follow-up strategies in future research of this kind.

To our knowledge, this is the first study to explore decisions on reconstruction after mastectomy in non-English-speaking Australian patients. As only less than a quarter of study respondents were of non-English-speaking background, we cannot draw reliable conclusions about reconstruction rates in this versus the English-speaking sub-group in our study, particularly as sample response bias may be a study limitation. However, the significantly lower reconstruction rate reported by respondents who spoke a language other than English at home ($n = 12$, 37.5%) compared to those who only spoke English at home ($n = 20$, 62.5%) is consistent with recently published research on clinical trial participation [41], indicating that it is the language barrier rather than the CALD status per se which may be the more important contributor to observed differences between non-English-speaking and English-speaking groups. This potential language barrier may also underpin other study findings, including our non-English-speaking participants being half as likely to have had reconstruction discussed with them prior to their mastectomy compared to English-speaking participants, and none of the non-English-speaking patients reporting having sought information on reconstruction from the Internet, potentially because it was not readily available in their preferred language.

Irrespective of language status, patients overwhelmingly wanted more information on reconstruction to help them in making their decision about reconstruction, including "understanding the pros and cons of reconstruction", "clear understanding of the risk and financial cost involved" and assurance "that the procedure is safe and there is no potential complications or side effects and not too costly". A decision aid will provide women with timely information about their breast reconstruction options. Such an aid will be an important prompt to facilitate patient-centred discussion with their surgeon. Communication skill training programs are now available to support communication with CALD patients [42].

Conclusion

Notwithstanding the low study response rate, both non-English-speaking and English-speaking patients wanted more information about reconstruction and more support from surgeons and breast care nurses to decide about reconstruction after mastectomy for breast cancer. We also found that non-English-speaking patients were less likely to have discussed reconstruction prior to their mastectomy. There is an urgent need for information about breast reconstruction, particularly for non-English-speaking patients, and a decision aid may be a useful tool for providing these patients with information in a way that facilitated an informed decision which takes into consideration their personal priorities and values.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

References

1. Ferlay J et al (2013) Cancer Incidence and Mortality Worldwide: IARC CancerBase. In: GLOBOCAN 2012 (online). International Agency for Research on Cancer, Lyon
2. AIHW (2016) Australian Cancer Incidence and Mortality (ACIM) books: breast cancer. AIHW, Canberra
3. Kwok C, White K (2011) Cultural and linguistic isolation: the breast cancer experience of Chinese-Australian women - a qualitative study. Contemp Nurse 39(1):85–94
4. Boehmke MM, Dickerson SS (2005) Symptom, symptom experiences, and symptom distress encountered by women with breast cancer undergoing current treatment modalities. Cancer Nurs 28(5):382–389

5. Ditsch N, Bauerfeind I, Vodermaier A, Tripp C, Löhrs B, Toth B, Himsl I, Graeser M, Harbeck N, Lenhard M (2013) A retrospective investigation of women's experience with breast reconstruction after mastectomy. Arch Gynecol Obstet 287:555–561
6. National Breast and Ovarian Cancer Centre (2010) National Breast and Ovarian Cancer Centre and Royal Australasian College of Surgeons National Breast Cancer Audit Public Health Monitoring Series 2008 Data. National Breast and Ovarian Cancer Centre, Surry Hills
7. Kocan S, Gursoy A (2016) Body image of women with breast cancer after mastectomy: a qualitative research. J Breast Health 12:145–150
8. Reuben BC, Manwaring J, Neumayer LA (2009) Recent trends and predictors in immediate breast reconstruction after mastectomy in the United States. Am J Surg 198(2):237–243
9. Cordeiro PG (2008) Breast reconstruction after surgery for breast cancer. N Engl J Med 359(15):1590–1601
10. Eriksen C, Frisell J, Wickman M, Lidbrink E, Krawiec K, Sandelin K (2011) Immediate reconstruction with implants in women with invasive breast cancer does not affect oncological safety in a matched cohort study. Breast Cancer Res Treat 127(2):439–446
11. Heneghan HM, Prichard RS, Lyons R, Regan PJ, Kelly JL, Malone C, McLaughlin R, Sweeney KJ, Kerin MJ (2011) Quality of life after immediate breast reconstruction and skin-sparing mastectomy - a comparison with patients undergoing breast conserving surgery. Eur J Surg Oncol 37(11):937–943
12. Mustonen P et al (2004) The surgical and oncological safety of immediate breast reconstruction. Eur J Surg Oncol 30(8):817–823
13. Handel N, Silverstein MJ, Waisman E, Waisman JR (1990) Reasons why mastectomy patients do not have breast reconstruction. Plast Reconstr Surg 86(6):1118–1122
14. Platt J, Baxter N, Zhong T (2011) Breast reconstruction after mastectomy for breast reconstruction. Can Med Assoc J 183(18):2109–2116
15. Schain WS, Jacobs E, Wellisch DK (1984) Psychosocial issues in breast reconstruction. Intrapsychic, interpersonal, and practical concerns. Clin Plast Surg 11(2):237–251
16. Schain WS et al (1985) The sooner the better: a study of psychological factors in women undergoing immediate versus delayed breast reconstruction. Am J Psychiatry 142(1):40–46
17. Lam TC, Winch CJ (2016) What would women choose when given a choice in breast reconstruction?. Plastic and reconstructive surgery. Global Open 4(9):e1062
18. Flitcroft K et al (2016) Documenting patterns of breast reconstruction in Australia: the national picture. Breast 30:47–53
19. Jeevan R, Mennie JC, Mohanna PN, O'Donoghue JM, Rainsbury RM, Cromwell DA (2016) National trends and regional variation in immediate breast reconstruction rates. Br J Surg 103(9):1147–1156
20. Chiu AS, Thomas P, Killelea BK, Horowitz N, Chagpar AB, Lannin DR (2017) Regional variation in breast cancer surgery: results from the National Cancer Database (NCDB). Am J Surg 214(5):907–913
21. Wong A et al (2014) Increasing breast reconstruction rates by offering more women a choice. Breast 84:31–36
22. Lee C, Hultman C, Sepucha K (2010) What are patients' goals and concerns about breast reconstruction after mastectomy? Ann Plast Surg 64(5):567–569
23. Manne S, Topham N, D'Agostino TA, Myers Virtue S, Kirstein L, Brill K, Manning C, Grana G, Schwartz MD, Ohman-Strickland P (2015) Acceptability and pilot efficacy trial of a web-based breast reconstruction decision support aid for women considering mastectomy. Psycho-Oncology 25(12):1424–1433
24. Murray CD, Turner A, Rehan C, Kovacs T (2015) Satisfaction following immediate breast reconstruction: experiences in the early post-operative stage. Br J Health Psychol 20(3):579–593
25. Sepucha KR, Fowler FJ Jr, Mulley AG Jr (2004) Policy support for patient-centered care: the need for measurable improvements in decision quality. Health Aff Suppl Variation: VAR54–62
26. Alderman AK, Hawley ST, Morrow M, Salem B, Hamilton A, Graff JJ, Katz S (2011) Receipt of delayed breast reconstruction after mastectomy: do women revisit the decision? Ann Surg Oncol 18(6):1748–1756
27. Hequet D et al (2013) Reasons of not having breast reconstruction: a historical cohort of 1937 breast cancer patients undergoing mastectomy. Springerplus 2:325
28. Cancer Australia (2016) Cancer Australia Statement - Influencing best practice in breast cancer. Cancer Australia, Surry Hills
29. National_Institute_for_Health_and_Care_Excellence (2009) Early and locally advanced breast cancer: diagnosis and treatment. NICE guidelines [CG80]. National Collaborating Centre for Cancer, Cardiff
30. Morrow M, Scott SK, Menck HR, Mustoe TA, Winchester DP (2001) Factors influencing the use of breast reconstruction postmastectomy: a national cancer database study. J Am Coll Surg 192(1):1–8
31. Desch CE, Penberthy LT, Hillner BE, McDonald MK, Smith TJ, Pozez AL, Retchin SM (1999) A sociodemographic and economic comparison of breast reconstruction, mastectomy and conservative surgery. Surgery 125(4):441–447
32. Polednak AP (2001) How frequent is postmastectomy breast reconstructive surgery? A study linking two statewide databases. Plast Reconstr Surg 108:73–77
33. Polednak AP (1999) Postmastectomy breast reconstruction in Connecticut: trends and predictors. Plast Reconstr Surg 104(3):669–673
34. South Western Sydney Local Health District, SWSLHD year in review 2015/2016. 2016
35. Alderman AK, Hawley ST, Morrow M, Salem B, Hamilton A, Graff JJ, Katz S (2011) Receipt of delayed breast reconstruction after mastectomy: do women visit the decision? Ann Surg Oncol 18(6):1748–1756
36. Alderman AK, Hawley ST, Janz NK, Mujahid MS, Morrow M, Hamilton AS, Graff JJ, Katz SJ (2009) Racial and ethnic disparities in the use of postmastectomy breast reconstruction: results from a population-based study. J Clin Oncol 27(32):5325–5330
37. Morrow M, Li Y, Alderman AK, Jagsi R, Hamilton AS, Graff JJ, Hawley ST, Katz SJ (2014) Access to breast reconstruction after mastectomy and patient perspectives on reconstruction decision making. JAMA Surg 149(10):1015–1021
38. Bell RJ, Robinson PJ, Fradkin P, Schwarz M, Davis SR (2012) Breast reconstruction following mastectomy for invasive breast cancer is strongly influenced by demographic factors in women in Victoria, Australia. Breast J 21(3):394–400
39. Ng SK, Hare RM, Kuang RJ, Smith KM, Brown BJ, Hunter-Smith DJ (2016) Breast reconstruction post mastectomy: patient satisfaction and decision making. Ann Plast Surg 76(6):640–644
40. Flitcroft K, Brennan M, Spillane A (2017) Decisional regret and choice of breast reconstruction following mastectomy for breast cancer: a systematic review. Psychooncology
41. Smith A, Agar M, Delaney G, Descallar J, Dobell-Brown K, Grand M, Aung J, Patel P, Kaadan N, Girgis A (2018) Lower trial participation by culturally and linguistically diverse (CALD) cancer patients is largely due to language barriers. Asia Pac J Clin Oncol 14(1):52–60
42. Meiser B, Kaur R, Zilliacus E, Wong T, Woodland L, Tomkins S, Kissane D, Girgis A, Butow P, Hale S, Perry A, Aranda SK, Shaw T, Tebble H, Goldstein D (2017) Evaluation of an online communications skills training programme for oncology health care professionals working with patients from minority backgrounds. Asia Pac J Clin Oncol 13:66