Awareness and Acceptability of Breast Reconstruction Among Women With Breast Cancer: A Prospective Survey

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PURPOSE Quality of life has become an integral aspect of the management of breast cancer. Many women still need to undergo a modified radical mastectomy (MRM). Factors affecting the choice a woman makes to undergo breast reconstruction (BR) are unclear and are hypothesized to be influenced by socioeconomic factors. We conducted a survey to evaluate the awareness and acceptability of BR among women with breast cancer at our institution.

METHODS A novel questionnaire was designed and served to 3 groups of women: planned for MRM, follow up (FU) post-MRM, and FU post breast-conserving surgery.

RESULTS Responses were analyzed from 492 women. Of these, 280 (56.91%) were planned for MRM and 212 (43.08%) women were on FU. Almost 45% women were older than 50 years of age, and literacy rate was 87.6%. More than 70% were homemakers and 15 women (3%) were unmarried. The aspects evaluating awareness of BR suggested that 251 (51.01%) women had knowledge about BR. Major source of information was the surgeon (45.81%) and media (32.87%). About 80% women on FU post-MRM did not want reconstruction, and 55% did not opt for BR as they had coped with the mastectomy and did not feel the need for BR. Only 6% cited family or financial reasons and 10% cited recurrence concerns. Among women planned for surgery, 65.71% had not considered BR. When questioned, 25 (12.88%) felt influenced by cost, 102 (52.58%) felt they did not need it, and 20 (10.31%) were worried it would affect treatment.

CONCLUSION Our study shows high awareness regarding BR, but only 27.89% women opt for BR independent of economic issues. We recommend all patients should be counseled about the reconstructive options when their MRM is planned.

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INTRODUCTION

Breast cancer is the most common cancer affecting women in India, with more than 100,000 new women with breast cancer diagnosed annually.2 There is now greater stress on quality of life among patients undergoing breast surgery. Improving the cosmetic outcome is also one of the major objectives of the breast surgeon. Despite oncoplasty gaining popularity, 70% women undergo a mastectomy in India, which still remains most common procedure offered for all stages of breast cancer.3 This could be attributed to the late stage at presentation, myths and misconceptions among women (where removing the breast is equivalent to decreasing the chances of recurrence), and infrastructural inequalities (lack of radiation units). Unsurprisingly, there is little to no knowledge of Knowledge, Attitude, and Practices of Breast Reconstruction Surgery in a developing nation such as India.

Multiple prospective and retrospective studies have highlighted the benefit of reconstruction in either an immediate or delayed setting in improving healthrelated quality of life.4-8 The benefits range from improving body image to decreasing psychosocial morbidity in terms of general mental health, anxiety, and self-esteem.9 The benefits of reconstruction last beyond the immediate postoperative period and are best seen when the entire process of reconstruction is complete.

The decision about breast reconstruction (BR) can be complex and multifaceted. By better understanding of these factors that influence decision making, one can improve or influence decision making in women undergoing breast cancer surgery and also alter the approach of the treating surgeon. A commonly used methodology for health-seeking behavior research is Knowledge, Attitude, and Practices (KAP) surveys that take into account the knowledge, attitude, and

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CONTEXT

Key Objective

To understand the awareness and practice of breast reconstruction (BR) among Indian women with breast cancer. This is the first Indian study that has evaluated awareness about BR and delved into the reasons for the choices and myths surrounding reconstruction.

Knowledge Generated

This cohort of women have a high awareness of BR, but little willingness to undergo the same. Cost constraint has traditionally been assumed to be the primary deterrent. This survey brought up fear of recurrence or inability to detect recurrences, coping skills, and lack of priority of cosmesis as more common reasons.

Relevance

The impact of cosmesis on quality of life has often been discussed. We need to dispel the myths around BR and the role of the treating surgeon need to spearhead the efforts in counseling women regarding reconstruction options.

practice of a specific population in relation to a particular topic.

In context of biomedical concepts, the evaluation is based on the community's knowledge of the concepts. Any deviation or digression from biomedical concepts is categorized as beliefs. However, for classification of attitude, we need to understand how beliefs, feelings, and values interact. Attitude entails an already predisposed view to think, feel, and act in a particular manner.

KAP surveys are deployed to understand how communities employ preventive measures or alternate healthcare options. By use of conjecture, inference is drawn on how people react or are expected to react based on their predisposition rather than actual practices. This study aims to highlight the KAP regarding reconstruction among women undergoing breast surgery from a single tertiary center in India.

METHODS

A novel questionnaire was designed by experts in breast oncology and reconstruction at our institution. This was served to women presenting to the breast clinic. Three groups were interviewed: cohort 1, women planned for a modified radical mastectomy (MRM); cohort 2, women on follow up (FU) post mastectomy; and cohort 3, women on FU post breast-conserving surgery (BCS). The questionnaire was administered in the language they best understood to record various socioeconomic aspects that may affect their choice to opt for breast reconstructive surgery.

The survey domains were classified into the following groups: awareness of BR, conceptual knowledge, attitude, and perception per cohort. The survey created was divided into two sections: section 1 was common to all 3 cohorts and captured patient demographic data, including marital status, education, occupation, family history, awareness of BR, types of reconstruction, contralateral breast surgery for cosmesis, and nipple areolar surgery. In addition, they were

questioned on who the source for the above information on awareness was. Each cohort was then served a second section that was unique to their concerns. Participants of cohort 1, planned for an MRM, were asked whether they were offered reconstruction at this current time when surgery for the primary tumor is planned and details regarding the same. Cohort 2 included women post MRM who visited the FU clinic (range 1-5 years on FU). The questions in this section focused on whether they would opt for reconstruction now while on FU and details regarding the same. Finally, cohort 3 included women from the FU clinic who had undergone a BCS and were on follow-up for anywhere from 1 to 5 years. The section for this group questioned their current satisfaction with post-BCS cosmesis and the awareness related to options regarding corrections or reconstruction post BCS. Of all the patients screened, we had an 85% participation rate. The study was approved by institutional ethics committee.

RESULTS

Demography

During the study period, 492 women were interviewed and their responses were analyzed. Of these, 280 (56.9%) were awaiting surgery and planned for an MRM, 100 (20.3%) had undergone a mastectomy and were on FU, and 112 (22.8%) had undergone breast-conservative surgery and were on FU. In the overall cohort, 91 (18.4%) were younger than 40 years of age, 178 (36%) women were between 40 and 50 years of age, and 223 (45.1 %) were older than 50 years of age. About 12.4% of women were illiterate (received no schooling) and 50.40 % women had varying levels of education. Only 37.19 % of women provided history of education beyond high school. More than 70% of the women in this cohort were homemakers. Fifteen (3%) women were unmarried, 28 (5.7%) women were nulliparous, and 355 (72.15%) women in the study population had two or more children (Table 1).

TABLE 1. Demographic Details

Characteristic	Cohort 1 (for Surgery) n = 280	Cohort 2 (MRM FU) n = 100	Cohort 3 (BCS FU) n = 112	Total N = 492 (%)
Age, years				
> 40	53	10	28	91 (18.4)
40-50	85	43	50	178 (36)
> 50	142	47	34	223 (45.1)
Education				_
Illiterate	49	8	4	61 (12.4)
Some schooling	157	47	44	248 (50.40)
Higher education	74	45	64	183 (37.19)
Occupation				
Home makers	222	70	67	359 (72.96)
Marital status				
Unmarried	8	3	4	15 (3)
Married	239	94	107	440 (89.43)
Divorced or separated	8	2	1	11 (2.23)
Parity				
Nulliparous	13	8	7	28 (5.7)
One child	42	22	32	96 (19.51)
Two or more children	225	70	73	355 (72.15)

Awareness

Of the overall cohort, 251 (51.01%) of these women were aware of options of BR. However, only 139/251 (52.19%) were aware of reconstruction options at the time of surgery.

The treating surgeon was the prime source of this information, with 115/251 (45.81%) of women reporting that the treating doctor was their first source of information. Other common sources of information included digital or print media, reported by 81 (32.27%), and family and

friends, reported by 60 (23.9%). Only 72/251 (28.68%) of the women reported knowledge of expanders or implants and 138/251 (54.98%) were aware of about autologous method of reconstruction (Table 2).

Conceptual Knowledge About Cosmesis

Majority of the women, 378/492 (76.82%), stated that they were not aware of the fact that their breast post surgery and reconstruction would appear similar to opposite breast (ie, matched for shape and size). Also, 397/492 (80.7%) of the

TABLE 2. Aware of Breast Reconstruction

Knowledge about Breast Reconstruction	Total N = 492	Proportions (p)	Standard Deviation
Aware of reconstruction options	251	0.510	0.022
Aware at the time of primary surgery	139	0.282	0.020
Knowledge of implants or expanders	72	0.146	0.015
Knowledge of autologous flaps	138	0.280	0.020
Aware that shape or size would be similar	114	0.231	0.019
Aware of contralateral corrective options	95	0.193	0.017
Aware of NAC reconstruction options	76	0.154	0.016
Source of information (more than one option)			
Treating physician	115	0.458	0.022
Digital and print media	81	0.322	0.021
Family and friends	60	0.239	0.019

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TABLE 3. Reasons Cited for Choices

Cohort 1: scheduled for MRM

Survey Question	Total	Proportions (p)	Standard Deviation
Offered primary reconstruction	96	0.342	0.028
Opted for reconstruction	40	0.416	0.042
Not offered primary whole breast reconstruction	184	0.657	0.002
Would consider reconstruction if offered (n = 184)			
Yes	46	0.25	0.031
No	118	0.641	0.029
Not sure	20	0.108	0.012
Reasons want reconstruction (N = 86) (more than one option)			
Cosmesis	22	0.255	0.047
Confidence	33	0.383	0.052
Family pressure	19	0.220	0.044
Reasons don't want reconstruction or unsure (N = 194) (more than one option)			
Did not need	102	0.525	0.035
Not a priority	37	0.190	0.028
Financial constraints	25	0.128	0.024
Concerns of oncological safety	20	0.103	0.021
Family pressure	6	0.030	0.012
Willing for contralateral surgery (N = 280)			
Yes	120	0.428	0.029
No	160	0.571	0.029
Cohort 2: nost MPM on FII (n = 100)			

Cohort 2: post MRM on FU (n = 100)

	Total	Proportions (p)	Standard Deviation
Would consider secondary reconstruction			
Yes	20	0.2	0.04
No	69	0.69	0.046
Not sure	11	0.11	0.031
Reasons want reconstruction (N = 20) (more than one option)			
Cosmesis	20	1	0
Confidence	20	1	0
Family pressure	2	0.1	0.067
Reasons don't want reconstruction or unsure (N = 80) (more than one option)			
Did not need	44	0.55	0.055
Not a priority	9	0.112	0.035
Financial constraints	6	0.075	0.029
Concerns of oncological safety	10	0.125	0.036
Family pressure	2	0.025	0.017
Willing for contralateral surgery (N = 100)			
Yes	7	0.07	0.025
Not sure	17	0.17	0.037
No	76	0.76	0.042

(Continued on following page)

TABLE 3. Reasons Cited for Choices (Continued)

Cohort 3: post BCS on FU (n = 112)

	Total	Proportions (p)	Standard Deviation
Satisfied with cosmetic outcome			
Yes	92	0.821	0.036
No	20	0.178	0.036
Willing for surgical intervention	8	0.071	0.024
Offered cosmetic correction (n = 20)			
Yes	9	0.45	0.111
No	11	0.55	0.111
Not willing for any surgical procedure to correct cosmesis if needed (n = 112) (more than one option)			
Not a priority	69	0.616	0.045
Financial constraints	01	0.008	0.008
Family pressure	02	0.017	0.012

Abbreviations: BCS, breast-conserving surgery; FU, follow-up; MRM, modified radical mastectomy.

women did not know that the unaffected breast could be operated upon to acquire a good cosmetic result. Awareness of nipple areola reconstruction was also very low (76/492 [15.44%]) among these women (Table 2).

Analysis Per Cohort

Cohort 1: prior to surgery. In the cohort of 280 women who were interviewed before their MRM, 184 (65.5%) stated that they were not offered or explained about the option and feasibility of BR (Table 3). Of these 184, 46 (25%) women stated that they would consider reconstruction, 118 (64.13%) were not in favor, and 20 (10.87%) were unsure.

Among the 46 women who would consider reconstruction, 22 (47.82%) women felt that reconstruction would make them look better, 33 (71.74%) stated that they would be more confident post reconstructive surgery, and 19 (41.30%) reported that the husband or family wanting the reconstruction was the main reason driving their decision.

Of the 280 women, 194 women did not consider the option of reconstruction, 102 (52.58%) women felt they did not need it, 37 (19.07%) women felt that reconstruction was not a priority for them, 25 (12.88%) women reported financial concerns, and 20 (10.31%) women feared that reconstruction would adversely affect the oncological outcomes. Only 6 (3.09%) stated family concerns as a reason driving their decision.

Eighty-six (30.71 %) of the women scheduled for surgery suggested that they would consider postmastectomy reconstruction. On analyzing factors motivating the choice for reconstruction, 22 (25.58%) women felt that reconstruction would make them look better, 33 (38.37%) stated that

they would be more confident post reconstructive surgery, and 19 (22.06%) reported that the spouse wanting the reconstruction was the main reason driving their decision.

Factors that could affect the KAP of women undergoing reconstruction were analyzed. Financial concerns were raised by only 42/194 (21.64%) women who said they would opt for reconstruction if it was free or cheaper. A large majority of women, 108 (55.67%), stated that financial security would not change their mind and 51 (26.29%) were unsure. Assurance that additional surgery would not affect the oncological outcome or affect cancer detection would alter the decision in 76 (39.17%) women and 40 (20.61%) still remained unsure.

We also evaluated the role of visual aids and interaction with women who have undergone reconstruction; 36 (12.8%) said that they would be willing to change their mind if they interacted with patients who had already undergone reconstruction. One hundred fifteen (41%) patients stated that they would reconsider if they were properly counseled with visual aids. However, only 90 (32.14%) women were willing to come, interact, and educate other women about reconstruction options if and when called upon to do so.

Analysis of the attitude of women regarding surgery of the opposite breast revealed that 160 (57.14%) stated that they would not consider surgery to the normal breast to match shape and size of the affected breast. Additionally, 11 (3.92%) women believed that it would affect feeding of the next child, 29 (10.35%) were worried about complications, and 21 (7.5%) thought it would adversely affect detection of cancer in the normal breast.

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Cohort 2: post MRM on FU. One hundred women who had undergone an MRM were interviewed on FU visits. Ten percent of this cohort were younger than 40 years of age and 43% were between 40 and 50 years. When women were asked for desirability of secondary reconstruction, only 20% (20/100) were keen and a majority (69%) did not consider. Among these 20 women, 4 (20%) were younger than 40 years of age, 10 (50%) between 40 and 50 years, and 6 (30%) older than 50 years of age. All 20 felt it would make them more confident and two suggested their spouse would want it.

Of the 80 women who were either unwilling or unsure for secondary reconstruction, 10 (12.5%) cited concerns of oncological safety and fear of future recurrence, 9 (12.25%) felt it was not a priority, 6 (7.5%) cited financial concerns, and 44 (55%) felt they did not need it. Importantly, 11/80 (13.75%) of the women were willing to reconsider their decision if they were shown results of already operated women and allowed to interact with them. Only 7% of these women suggested willingness to undergo surgery for the contralateral breast if needed for cosmetic outcome.

Cohort 3: post BCS on FU. In 112 women who had undergone breast-conservative surgery, 28/112 (25%) were younger than 40 years of age, and 49/112 (44.64%) were between 40 and 50 years of age. Overall, 20 (17.85%) women were unhappy with their long-term cosmetic outcome; however, only 9/20 (45%) had been offered correction by their surgeon. Of the 112, 74 (66.07%) were unaware of options to correct or improve cosmetic outcomes. Of the 20 unhappy with the cosmetic outcome, 8 (40%) were keen on corrective procedures. Of these, 5/8 had asked for it of their own accord (62.5%).

The main reason for not wanting to undergo cosmetic correction was the women's perception of cosmesis not being a priority (69 women), financial constraints, and family reasons. However, 46/112 (41.1%) women stated that interacting with women who have already been operated would help them in understanding cosmesis and alter their decision.

DISCUSSION

The entire cohort is representative of women with breast cancer in India wherein the median age is 49 years and in this cohort, 36% women were between 40 and 50 years of age. An analysis of the quantitative data obtained from this study sheds light on the factors that affect decision making both for and against BR among Indian women. When opting for BR surgery, women appear to be influenced by prior knowledge, counseling from the surgeon, norms prevalent in the society, body appearance, and their partner's preference.

The role of the treating surgeon in counseling women regarding reconstruction options needs to be considered as relevant as informing them about adjuvant therapy

recommendations. Greenberg et al¹⁰ documented that the single greatest predictor a woman's choice to undergo BR was if reconstruction had been mentioned by the breast surgeon in the initial consultation. Others have documented that multidisciplinary tumor meetings before surgery also influence the ultimate surgical choice. ^{11,12} Hawley et al¹³ stated that referral to a plastic surgeon prior to initiation of treatment also significantly affected reconstruction practices. Appropriate preoperative counseling is a window of opportunity, and a lack of effort from the surgeon can deprive women of quality-of-life benefits. In the entire study cohort, more than 50% women were aware of BR; however, only 45.81% of those reported that the treating surgeon was the prime source of information.

Another Indian study by Kothari et al¹⁴ reported that only 242 of 1,000 women they surveyed from a metropolitan city in India were aware about BR after treatment for breast carcinoma.

Major factors driving women's decisions for considering reconstruction included an improved cosmetic outcome (25.58%) and a greater sense of self-confidence (38.37%). These results are similar to those from Western literature. However, 22% of our patients scheduled for MRM (cohort 1) reported that the spouse wanting the surgery being a factor driving their decision. This possibly indicated the negative impact of an MRM on their sex life. This is in contrast to certain studies from the West where women opted for reconstruction for themselves rather than for their partners. In addition, one of the main reasons for wanting reconstruction in the West is the inconvenience and problems associated with wearing an external prosthesis. Head

This survey has revealed some misconceptions among Indian women in reference to BR. In the authors' opinion, the lack of importance given to cosmesis, both by clinicians and patients, could deprive the women of potential benefits of reconstructive surgery. Reconstruction is still considered as an elective cosmetic procedure that may increase hospital stay, and the belief that it would be associated with greater recurrence needs to be addressed.

Fortunately, almost 41% of the women who were awaiting surgery (cohort 1) were willing to reconsider their decision if they were adequately counseled and were given visual aids to give them a realistic understanding of post reconstruction results. This again highlights the importance of counseling and the indispensable role of the treating surgeon. The role of the treating surgeon as gatekeepers when it comes to women opting for BR is also highlighted in our study.²¹

A contralateral procedure on the unaffected breast to improve symmetry is still uncommon in India. In this survey, 66.57% of the women refused corrective surgery on the unaffected breast (almost two third of the women). This is in contrast to reported literature from the West where contralateral reduction or augmentation procedures and even

prophylactic mastectomies are more commonly offered and performed.²²⁻²⁴

In the second cohort of 100 women who had undergone an MRM and were interviewed on FU, only 20% said they would consider secondary reconstruction. The remaining patients possibly have high coping skills or are satisfied with the external prosthesis. This again is different from Western reports, highlighting a cultural difference. ²⁵⁻²⁷ In both planned for MRM and post MRM FU cohorts, BR choices were not related to only financial constraints, but largely to the lack of women's awareness on safety of reconstruction and prioritization of cosmesis.

Additionally, in cohort 3 (post BCS on FU), almost 17.85% women were unhappy with their long-term cosmetic outcome, of which only eight were keen on corrective procedures. Long-term poor cosmetic outcomes may be related to older surgical techniques, seroma cavity fibrosis, and long-term radiation changes.²⁸ Newer oncoplastic techniques may allow for better cosmetic results and reduce the dissatisfaction with BCS cosmesis.²⁹

The New York State Breast Cancer Provider Discussion Law, 2010, mandated that the treating surgeon provide reconstructive options post mastectomy to improve awareness among patients.³⁰ Fu et al³¹ studied the impact of this law and reported that there was a significant increase in percentage of women seeking reconstruction from 49% in 2008 to 60% in 2014 post the passage of the bill. Incorporation of reconstructive options in the National Breast Cancer Management Guidelines and affordable surgical

charges could improve awareness and encourage women to undergo reconstruction.

To the best of our knowledge, this is the first study attempting to understand the KAP of BR among Indian women. Strengths of this study are the reflection of a real-life situation, over a fairly large, nonselected population. The questions were asked in the native language of the patient, with a set of specific questions for each cohort of patient.

There are a few limitations to our study. This study was from a tertiary cancer center and may not be reflect all regions across the country. A recall bias may have been introduced because of the self-reported nature of the observed variables, as a women's recall of their encounters with clinicians may vary with time or be influenced by their treatment experiences. The questionnaire prepared by the authors is not standardized and caters to the social, cultural, and beliefs of the population visiting the breast clinic.

In conclusion, our study shows high awareness regarding BR in women being treated for breast cancer. However, only 27.89% women opt for whole BR options independent of economic issues. Counseling for reconstruction should start at the first consultation, giving them adequate time to think over the options. All patients should be made aware of the reconstructive options when their surgery is planned. Additional visual aids and counseling may aid in guiding the decisions and improving acceptance of reconstruction rates among women undergoing surgery for breast cancer.

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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