

# Perspectives of Women Who Forgo Post-mastectomy Breast Reconstruction: A Mixed Methods Analysis

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**Background:** Despite a growing body of evidence suggesting improved psychosocial well-being and survival after post-mastectomy breast reconstruction (PMBR), rates remain stagnant at approximately 40%. Although PMBR access and utilization have been well reported, there is much less known from the point of view of women who decide not to undergo PMBR. This study uses a mixed methods approach to fill that gap by investigating the patient-level decisions that lead to foregoing PMBR.

**Methods:** A concurrent triangulation model under mixed methods research (MMR) was employed using in-depth qualitative interviews and the BREAST-Q questionnaire. Interviews were conducted until data saturation was reached and were analyzed using iterative methodologies under the grounded-theory framework. Reliability checks included inter-rater reliability using Cohen's kappa statistic (mean kappa = 0.99) and triangulation.

**Results:** Interviews with 8 patients who declined PMBR revealed (1) lack of trust in plastic surgeons; (2) reliance on self-developed support; (3) desire to resume normal life; (4) perceived lack of equivalency between reconstructed and natural breasts. Concurrent triangulation between the data revealed dissonance between the BREAST-Q scores for psychosocial well-being and reported levels of satisfaction.

**Conclusions:** Women in this study highlighted certain deficits in the current pathway to reconstruction: lack of trust, resources, and counseling. Such feelings of suspicion and reported opposition to PMBR are at odds with low scores for satisfaction with breasts and sexual well-being. These findings can be used to guide efforts that engender confidence, provide support, empower vulnerable patient groups, and increase utilization of PMBR. (*Plast Reconstr Surg Glob Open* 2021;9:e3203; doi: 10.1097/GOX.0000000000003203; Published online 22 February 2021.)

## INTRODUCTION

Breast cancer is the most commonly diagnosed cancer in women worldwide, and affects approximately 1 in 8 women in the United States.<sup>1,2</sup> Post-mastectomy breast reconstruction (PMBR) is an elective treatment option that is associated with improved psychosocial well-being.<sup>3-9</sup> In recognition of

its benefits, the United States Congress passed the Women's Health and Cancer Rights Act (WHCRA) in 1998, mandating insurance coverage for reconstruction and thereby lowering the access barrier to reconstructive care.<sup>10</sup> However, despite legislative and educational efforts to improve utilization, rates of PMBR remain stagnant at approximately 40%.<sup>10</sup> This plateau suggests that there remain unexplained factors that influence receipt of PMBR.

Medical decision-making is a multifaceted process, and available research demonstrates that fewer than half of the patients report that their decisions about PMBR were informed and consistent with their preferences.<sup>11</sup> Patient preferences and medical decisions are guided by socioeconomic status, race, and ethnicity: African American and Latina women are less likely to undergo PMBR.<sup>12,13</sup> Research also shows that having an incomplete understanding of the available choices and making medical choices that are inconsistent with one's preferences can lead to decision regret and reduced quality of life.<sup>14,15</sup>

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Despite the complexity of medical decision-making as it concerns PMBR, the current literature mostly quantifies patient experiences and satisfaction. Viewpoints can be better explored using qualitative research techniques, especially in the realm of sensitive topics like breast reconstruction, to offer a deeper understanding of the patient experience.<sup>16,17</sup> A majority of literature focuses on post-operative outcomes of women who received PMBR and largely ignores the experiences of the majority of women who do not receive reconstruction.<sup>18</sup> A recent study looking at barriers to reconstruction among rural women found that this population has unique information needs.<sup>19</sup> In this study, we attempt to fill the gap in literature by exploring perspectives of women who declined PMBR by using mixed methods: qualitative patient interviews and quantitative BREAST-Q. A comprehensive understanding of pre-operative barriers to PMBR can be used to guide efforts that promote trust, provide support, empower vulnerable patient groups, and perhaps increase utilization of PMBR.

## METHODS

### Sampling and Recruitment

Purposive sampling was used to identify 69 patients within the MedStar Health network who had undergone mastectomies within the last 5 years but no reconstruction. We selected participants from 2 groups: those who were referred to and met with a plastic surgeon preoperatively, and those who were referred to a plastic surgeon but declined the appointment. Following approval from the MedStar Georgetown Institutional Review Board (STUDY00000667), a recruitment letter was mailed to potential participants. Informed consent was obtained before starting the interview. Participants were given the option to do the interview in-person or over the phone. We offered participants the choice to participate in the interview remotely due to the sensitive nature of the topic and the wide geographical area covered. Participant recruitment and the analytic process were continued until data saturation was reached, and additional interviews did not yield new information. Participants were offered a \$50 gift card as compensation for their time.

### Study Design

A mixed methods design involving in-depth qualitative interviews and the BREAST-Q questionnaire was utilized. A semi-structured qualitative interview guide was developed to explore multilevel factors at the (1) patient, (2) physician, and (3) hospital level that may have influenced their decision. Each interview lasted approximately 90 minutes and participants were asked to complete the BREAST-Q questionnaire. The first author (TS) conducted all the interviews.

### Participants

Of the 69 women contacted, 8 enrolled in the study (response rate = 11.6%). In-depth interviews and BREAST-Q surveys were conducted with them (Fig. 1). The study population consisted of women who received a referral to plastic surgery but choose to forgo PMBR. Women were stratified into 2 groups based on utilization

of the referral to plastic surgery or lack thereof. Within our sample, 4 women were seen in consultation by a plastic surgeon and 4 women declined to see a plastic surgeon (Table 1). Pseudonyms are used to protect patient privacy.

### Data Analysis

Qualitative interviews were digitally recorded, transcribed verbatim, and imported into NVivo 12 (QSR).<sup>20</sup> We employed the constant-comparison technique within the grounded-theory framework of data analysis. This inductive methodological approach involves a continual comparison of themes and concepts within and between the data sets.<sup>21–25</sup> In accordance with this data analysis technique, we engaged in open, axial, and selective coding. Open coding consists of reading transcripts line-by-line to describe the text and to identify recurring categories and sub-categories in the data.<sup>25</sup> The first author engaged in open coding to create a preliminary coding structure for the co-investigators to follow. The open codes were then used as a basis to develop more focused codes known as axial codes. Finally, we engaged in selective coding, where we decided on the core concepts.

Quantitative BREAST-Q scores were calculated using the Q-score program, which converts raw survey scores of 1 through 4 or 5 to continuous scores of 0–100. Higher scores signify patients were more satisfied, or more strongly agreed with a specific statement. Within mixed methods research, we utilized the concurrent triangulation design, which seeks convergence or corroboration of results from different methods (Fig. 2).<sup>21</sup>

### Rigor and Trustworthiness

To ensure inter-coder reliability, first (TS) and second (LG) authors met regularly to iteratively discuss the data and refine the emerging themes (Cohen's mean kappa statistic = 0.99). The principal investigator (KLF) evaluated whether the final coding scheme accurately reflected the data.

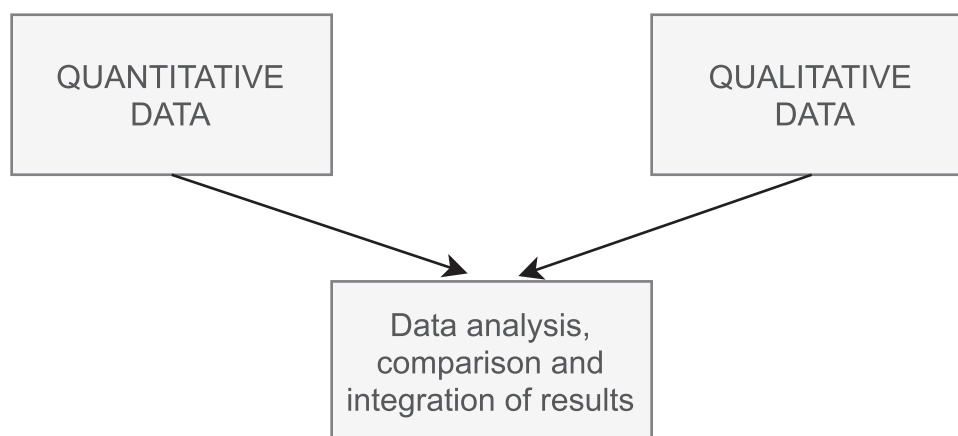
## RESULTS

### Demographics

Of the 8 women who participated in our study, 5 were White, 2 were African American, and 1 was Asian (Table 1). Most women had invasive ductal carcinoma (stages ranging from 0 to 3), and most did not receive adjuvant or neo-adjuvant therapy. Of them, 4 saw a plastic surgeon and the other 4 declined. Women who had consultation with a plastic surgeon were more likely to be younger, employed, have higher levels of education (bachelor's degree and above), mostly had unilateral mastectomies, and were White. Conversely, women who declined plastic surgery follow-up were older, retired, had lower levels of education, had bilateral mastectomies, and were predominantly women of color. Among our cohort, 7 women were married and 1 woman was widowed.

### Quantitative BREAST-Q Results

BREAST-Q sum scores were converted to equivalent Rasch Transformed Score (scale 0–100) and higher



**Fig. 1.** Depiction of the concurrent model of triangulation under mixed methods research employed to analyze qualitative and quantitative data.

scores indicate better outcomes (Table 2). Scores are reported as means. Mean scores for psychological well-being were comparable for both groups of women (68.3 for those who declined versus 68 for those who attended plastic surgery consultation). Satisfaction with the breast was slightly higher in women who declined (52.8) versus those who attended plastic surgery consultation (51.5). Women who met with a plastic surgeon had higher scores for their breast surgeon compared with those who declined (82.8 and 71, respectively). Of the 4 women who opted for a visit with a plastic surgeon, their scores for plastic surgeons (57.3) were lower than that of breast surgeons (82.8).

#### Qualitative Interview Results

Several findings emerged from the qualitative data, including: (1) physician distrust was salient; (2) perceived lack of equivalency between reconstructed breasts and natural breast and presumed parity between reconstructive and cosmetic surgery; (3) reliance on self-developed

support networks and resources; (4) desire to resume a normal life. Results from triangulation of quantitative and qualitative data revealed dissonance between BREAST-Q reported and self-reported satisfaction. These findings are detailed and discussed further below.

#### Physician Distrust Was Salient

Most women expressed distrust about surgeons and had reservations about their motivations. The surgeon-patient trust was weakened by the office environment and the display of advertisement material.

**ANNIKA:** At my appointment with the plastic surgeon there were advertisements from these different companies... So, you can't help but feel like "Am I a marketing target?"

Women who met with plastic surgeons to explore their options often had negative experiences, which amplified physician distrust. The negative experiences were rooted in discord between the medical advice of different physicians.

**Table 1. Participant Demographics and Characteristics at the Time of Mastectomy**

Pseudonym	Age	Race	Employment Status	Highest Education	Marital Status	Mastectomy Type	Breast Cancer Type	Breast Cancer Stage	Neo-adjuvant Therapy	Adjuvant Therapy
<i>Followed up with plastic surgeon</i>										
Rita	40s	White	Employed	Master's degree	Married	Unilateral	DCIS	0	No	Yes
Annika	50s	White	Employed	Master's degree	Married	Unilateral	Invasive ductal carcinoma	3	Yes	No
Julie	50s	White	Employed	Master's degree	Married	Bilateral	Invasive ductal carcinoma	2	No	No
Sabrina	40s	White	Employed	Bachelor's degree	Married	Unilateral	Invasive ductal carcinoma	1	No	No
<i>Declined follow-up with plastic surgeon</i>										
Katya	80s	African American	Retired	Some college	Widowed	Bilateral	Invasive ductal carcinoma	1	No	No
Elana	60s	Asian	Retired	Doctoral degree	Married	Bilateral	Invasive ductal carcinoma	2	No	Yes
Beth	70s	African American	Retired	High school degree	Married	Bilateral	DCIS	0	No	No
Brittany	50s	White	Employed	Master's degree	Married	Bilateral	Invasive ductal carcinoma	1	No	No

\*DCIS: ductal carcinoma in situ.

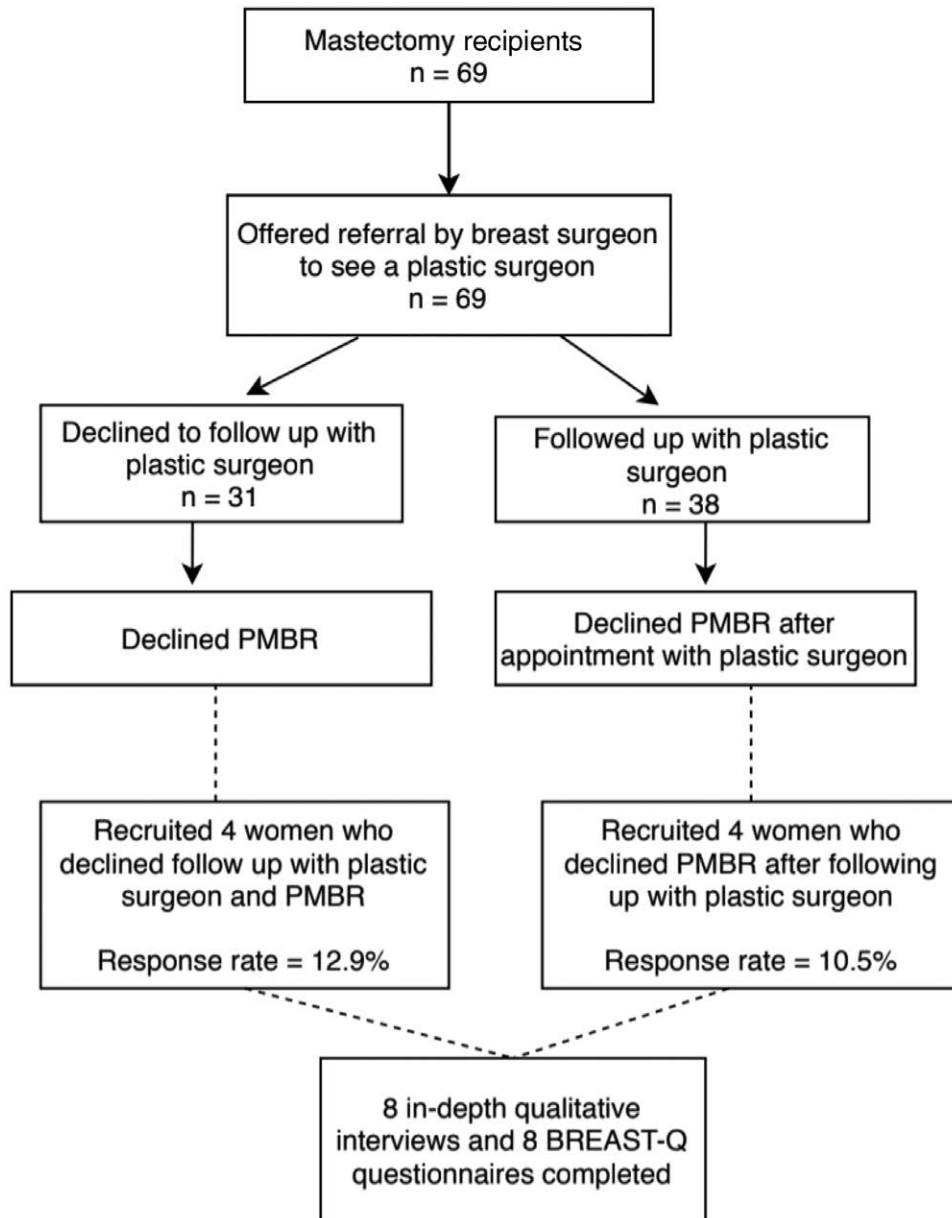


Fig. 2. Flow chart of participant recruitment.

SABRINA: I saw two plastic surgeons... the first one told me I had one week to decide, and he was pushing me to give him an answer...and then the second one said he could do the reconstruction even after 5-10 years... it was stressful, I didn't know what to do...you're going through so much.

**Perceived Lack of Equivalency between Reconstructed and Natural Breasts**

Women considering reconstructive surgery researched the aesthetic outcomes on the internet and by talking to others with similar experiences. Seeing photographs of the healing process and learning about the functionality of the reconstructed breast further dissuaded them.

Notably, several women emphasized the role breasts play in courtship, childrearing, and marriage. Once these roles were fulfilled, some women no longer needed their breasts.

ELANA: I don't need my breasts... for breast feeding... I don't think a reconstructed breast could do that anyway. I definitely don't need my breasts to define me. I feel comfortable enough with myself as a person.

**Reliance on Self-developed Support Networks**

Most of the women cultivated their own support networks and relied on friends and family for information and resources, not by choice, rather by necessity. The paucity of counseling and resources available to them at the

**Table 2. BREAST-Q Scores in Patients Who Followed Up with Plastic Surgeon Compared with Those Who Declined Plastic Surgery Follow-up**

Pseudonym	Age	Race	Psychosocial Well-being	Physical Well-being	Satisfaction with Breast	Sexual Well-being	Breast Surgeon	Plastic Surgeon
<i>Followed up with plastic surgeon</i>								
Rita	40s	White	50	100	34	43	100	46
Annika	50s	White	66	76	48	48	100	63
Julie	50s	White	77	72	53	59	61	70
Sabrina	40s	White	80	100	71	53	70	50
Mean BREAST-Q score $\pm$ SD			68.3 $\pm$ 13.6	87 $\pm$ 15.1	51.5 $\pm$ 15.3	50.8 $\pm$ 6.8	82.8 $\pm$ 20.3	57.3 $\pm$ 11.2
<i>Declined follow-up with plastic surgeon</i>								
Katya	80s	Black	58	100	44	36	59	—
Elana	60s	Asian	74	100	64	56	65	—
Beth	70s	Black	56	100	39	—	78	—
Brittany	50s	White	87	100	64	43	82	—
Mean BREAST-Q score $\pm$ SD			68.8 $\pm$ 14.6	100 $\pm$ 0	52.8 $\pm$ 13.1	45 $\pm$ 10.1	71 $\pm$ 10.8	—

\*Higher scores reflect better outcomes.

provider and system level drove them to seek out information themselves.

**ANNIKA:** I came with my questions and they were very pointed. I had to push him about the risks... If you don't do your own research... you're just going to end up with a very different decision. I will never know if I hadn't asked those questions where he [plastic surgeon] would have landed...

#### Desire to Resume Normal Life

Most women in our sample wanted to resume their normal life routine as quickly as possible, such as their careers, family life, or hobbies. Even though some considered reconstruction and took off time from work in anticipation, they later changed their mind in favor of a faster recovery and to preempt potential complications.

**BETH:** My first priority was getting this cancer out of my body. I care about how I look. But my priority was the medical aspect... I was frightened. It was about survival.

Some women were inherently opposed to elective surgery, citing excessive healthcare spending. Some had friends who had adverse outcomes following cosmetic surgery. Others wanted to use this experience to set an example of resilience.

**ELANA:** I learned a lot about reconstruction and the problems women were having. My sister has implants for cosmetic reasons ... they leak, they move, she has to get those darned things replaced... Oh my God, why give yourself all those problems?

#### Results from the Triangulation between Quantitative and Qualitative Data Revealed Dissonance

Results from the concurrent triangulation (Fig. 2) between the quantitative and qualitative data revealed discord between the reported satisfaction and BREAST-Q scores for psychosocial well-being. Women reported being made to feel isolated and strange for their decision to forgo reconstruction by healthcare providers and staff. They emphasized the need to de-stigmatize and respect the alternative to not get any reconstruction, despite lower satisfaction and psychosocial well-being scores.

**BRITTANY:** There is a lot of stigma. Women should be told whatever decision you make is fine. If you want to be flat, that is fine. Doctors should not box women in at the most vulnerable point in their lives...

**JULIE:** Stop acting like reconstruction is obvious choice and people are strange for not wanting it... tell women the percentage of women who don't get reconstruction ... tell them older women opt out of reconstruction.

## DISCUSSION

We chose a unique approach to understanding PMBR by exploring the perspectives of women who declined PMBR and specifically investigating the preoperative pathway under a mixed methods lens. Analyzing the qualitative data from this study yields a conceptual framework to better understand the multifaceted decision-making process against breast reconstruction among women in the United States. This research yields 5 key findings: (1) Lack of trust in surgeons was a hindrance to women opting for reconstruction; (2) Patients relied on self-developed support networks and resources; (3) Desire to resume normal life; (4) Perceived lack of equivalency between reconstructed and natural breasts; (5) Dissonance between the BREAST-Q scores for psychosocial well-being and reported feelings of regret.

This study sheds light on the specific concerns and fears harbored by women who forgo reconstruction and the salience of trust in a patient-physician relationship. Patients who declined reconstruction after plastic surgery follow-up had lower BREAST-Q scores for their plastic versus breast surgeon, highlighting that perhaps a perceived negative experience with plastic surgery could be a deterrent to PMBR. Previous research has demonstrated an association between rates of reconstruction and between-surgeon variation,<sup>26</sup> and our results provide qualitative evidence supporting that. Perhaps these findings can be used to implement physician-level interventions that promote trust and consistency. Additionally, our findings also support an association between lower BREAST-Q scores for breast surgeons and decreased utilization of referral to plastic surgery. These findings are consistent with prior research that suggested breast surgeons act as gatekeepers to reconstruction.<sup>27</sup>

Our findings also suggest that patients who decline PMBR may have unique information and support needs. Participants bore responsibility for obtaining information, and sometimes inaccurately assumed equivalency between PMBR and cosmetic augmentation. Our findings also suggest that the psychological turmoil that accompanies mastectomy remain unaddressed at the provider and system level. A future study could explore the outcomes of providing structured resources, and counseling at the system level, perhaps by establishing patient education and support programs within plastic surgery departments or outpatient clinics led by both surgeons and nurses, to help women adjust to life after mastectomy or PMBR. Understanding and addressing patients' specific needs could yield better patient-centered care, reduced feelings of alienation, and perhaps improve overall psychological outcomes.

Breast reconstruction confers an added quality of life improvement at 1 year after reconstruction equal to or beyond baseline.<sup>28</sup> Despite this, some women did not consider it as a viable treatment option once they fulfilled their familial duties or deemed themselves to be too old. Furthermore, certain cultural views consider breast reconstruction as a purely cosmetic procedure meant to *enlarge* breasts. These cultural biases coupled with anticipatory concerns about surgical procedures discouraged women from pursuing PMBR. Previous research suggests that the surgeon's perception of the patients' needs can differ significantly from the patients' perception of those same needs.<sup>29,30</sup> These findings further support our recommendation that there may be a role for nurse navigators, additional cultural competency training, and surgeons should consider each individual patient's disease status, cultural views, life circumstances, and values when assessing their information needs.

Lastly, and perhaps most importantly, under the concurrent triangulation mixed methods research design, we found dissonance between BREAST-Q scores and the in-depth interviews. The participants reported that they were satisfied with their decision to forgo reconstruction during the qualitative interviews, but the BREAST-Q scores did not support this sentiment. A recent study determined that the minimal important difference score of 4 points on the BREAST-Q scale (0–100) is clinically useful when assessing individual patient outcomes.<sup>31</sup> The BREAST-Q scores recorded in this study were lower than the established normative values seen in women who undergo PMBR. Research shows that the mean normative score for the "Satisfaction with Breasts" component of the scale was 58 among women after autologous reconstruction, whereas our data average was 51.5 and 52.8, for the groups that followed-up and declined follow-up, respectively.<sup>32</sup> Several studies have established a link between lower BREAST-Q scores for Satisfaction with Breasts, Psychosocial Well-being, and Sexual Well-being in women after mastectomy alone compared with mastectomy with reconstruction.<sup>6,9,33–35</sup>

In accordance with previous research, our sample also reported lower scores of sexual and physical well-being after mastectomy; however, these values were

lower than the established normative means, and those seen after both prosthetic and autologous reconstruction.<sup>6,9,28,33–35</sup> Therefore, the finding of dissonance between triangulation is salient because it lays the conceptual groundwork for acknowledging that factors such as physician distrust, fear, and lack of patient-tailored information contribute to the continued underutilization of PMBR.

Although these preliminary findings may provide valuable insight into the preoperative pathway to PMBR, they are subject to some limitations. First, we acknowledge that our small sample size limits the generalizability of the findings. Qualitative research has distinct parameters of scientific rigor and is well suited at answering questions about "why" and "how" rather than "how many" or "how much" that is afforded by statistical analyses. Data saturation, a methodological principle that depends on "the quality of data, the scope of the study, the nature of the topic, the amount of useful information obtained from each participant, the qualitative method and study designed used," is widely accepted to be the driver of sample size and can be reached anywhere between 5 and 50 qualitative interviews.<sup>36–40</sup> Second, recruitment was challenging, and recall and selection bias are inherent to this research design. To minimize recall bias, we limited recruitment to women who underwent mastectomies within the last 5 years. Future studies should adopt a multi-institutional collaborative approach to facilitate recruitment and minimize selection bias. Third, we acknowledge that there is a dearth of literature focusing on this population and a specific patient-reported outcome measure for women who decline PMBR does not exist. We used the BREAST-Q mastectomy specifically, which is designed to also be used for women who got mastectomy without reconstruction.<sup>33,34,41</sup> We recommend future studies investigate the experiences of a larger and more heterogeneous sample of women who forgo PMBR, to validate these preliminary findings, and perhaps eventually pave the way for a patient-reported outcome measure developed exclusively for this unique population.

## CONCLUSIONS

These findings lay the conceptual groundwork acknowledging that factors such as physician distrust and lack of resources and patient-tailored information contribute to underutilization of PMBR in certain populations. This disconnect is a substantial barrier to fostering trust, meeting patient needs, and thereby delivering effective patient care. These findings offer us an opportunity to address and potentially rectify residual feelings of dissatisfaction among women who declined PMBR, and perhaps assist them in making more informed decisions in the first place, without struggling to find information.

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