



ORIGINAL ARTICLE – GLOBAL HEALTH SERVICES RESEARCH

## “Going Flat” After Mastectomy: Patient-Reported Outcomes by Online Survey

Jennifer L. Baker, MD<sup>1</sup>, Don S. Dizon, MD<sup>2</sup>, Cachet M. Wenziger, MPH<sup>3</sup>, Elani Streja, PhD<sup>3</sup>, Carlie K. Thompson, MD<sup>1</sup>, Minna K. Lee, MD<sup>1</sup>, Maggie L. DiNome, MD<sup>1</sup>, and Deanna J. Attai, MD<sup>1,4</sup>

<sup>1</sup>Department of Surgery, University of California Los Angeles, Los Angeles, CA; <sup>2</sup>Brown University and the Lifespan Cancer Institute, Providence, RI; <sup>3</sup>Department of Medicine, University of California Irvine School of Medicine, Irvine, CA;

<sup>4</sup>UCLA Health Burbank Breast Care, Burbank, CA

### ABSTRACT

**Background.** The Going Flat movement aims to increase awareness and acceptance of mastectomy alone as a viable option for patients. Little is known about motivations and satisfaction with surgical outcomes in this population.

**Methods.** An online survey was administered to 931 women who had a history of uni- or bilateral mastectomy for treatment of breast cancer or elevated breast cancer risk without current breast mound reconstruction. Satisfaction with outcome and surgeon support for the patient experience were characterized using 5-level scaled scores.

**Results.** Mastectomy alone was the first choice for 73.7% of the respondents. The top two reasons for going flat were desire for a faster recovery and avoidance of a foreign body placement. Overall, the mean scaled satisfaction score was  $3.72 \pm 1.17$  out of 5. In the multivariable analysis, low level of surgeon support for the decision to go flat was the strongest predictor of a satisfaction score lower than 3 (odds ratio [OR], 3.85; 95% confidence interval [CI], 2.59–5.72;  $p < 0.001$ ). Dissatisfaction also was more likely among respondents reporting a body mass index (BMI) of  $30 \text{ kg/m}^2$  or higher (OR, 2.74; 95% CI, 1.76–4.27;  $p < 0.001$ ) and those undergoing a unilateral procedure (OR, 1.99; 95% CI, 1.29–3.09;  $p = 0.002$ ). Greater satisfaction was associated with receiving adequate information about surgical options (OR, 0.48; 95% CI, 0.32–0.69;

$p < 0.0001$ ) and having a surgeon with a specialized breast surgery practice (OR, 0.56; 95% CI, 0.38–0.81;  $p = 0.002$ ).

**Conclusions.** Most patients undergoing mastectomy alone are satisfied with their surgical outcome. Surgeons may optimize patient experience by recognizing and supporting a patient’s decision to go flat.

For women with early-stage breast cancer, similar oncologic outcomes are achieved with breast-conservation surgery (BCS), mastectomy alone (MA), and mastectomy with immediate breast reconstruction (IBR)<sup>1–5</sup>. Thus, maintaining long-term psychosocial and functional well-being is a vital consideration in deciding which surgical approach to pursue and often is sensitive to patient preference.

In recent years, mastectomy rates have increased in the United States, even among women who are candidates for BCS<sup>6,7</sup>. Published studies report conflicting results regarding the association of IBR with improved quality of life compared with MA<sup>1,3,8–13</sup>. Concerns about disproportionate underuse of reconstruction for vulnerable populations based on racial, geographic, and socioeconomic factors<sup>4,14–16</sup> has led to considerable efforts, including federal legislation, to ensure that patients are informed about reconstruction and have access to the procedure<sup>17</sup>. In addition, the current National Accreditation for Breast Centers (NAPBC) Standard 2.18 states: “All appropriate patients undergoing mastectomy are offered a preoperative referral to a reconstructive/plastic surgeon.”<sup>18</sup>

However, even with adequate information and access to reconstruction, women may elect to forgo reconstruction<sup>15</sup>. In recent years, advocacy groups and online communities have developed as part of the Going Flat movement, which

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D. J. Attai, MD  
e-mail: dattai@mednet.ucla.edu

aims to increase awareness and acceptance of MA as a viable option and to provide information and support for patients not interested in IBR<sup>19–22</sup>. One concept identified from this movement is “flat denial,” whereby surgeons advise against or do not offer the option of no reconstruction after mastectomy or leave excess tissue to facilitate future reconstruction against the patient’s wishes<sup>19</sup>.

We were interested in understanding whether the experiences of patients who are active in the Going Flat communities reflect those reported in the literature. In the current study, we conducted an online survey to identify correlates of satisfaction with surgical outcomes among women active in these communities who had undergone mastectomy without reconstruction. We also sought to assess motivating factors for going flat and to characterize and measure the experience of flat denial.

## METHODS

### *Survey Development*

A patient experience survey was developed based in part on a conceptual framework for question development related to the impact of long-term conditions and the experience of services and support<sup>23</sup>. The initial survey items were chosen based on literature review including prior work evaluating decision support for patients who do not desire breast reconstruction<sup>22</sup>. The survey was further refined after discussions with a focus group of breast cancer patient advocates. The patient advocates were chosen for their personal surgical experience, research background, and/or leadership positions in breast cancer and going flat advocacy organizations and social media communities. After development of the survey, it was pretested by four physicians and four patient advocates. The full survey is available in [Appendix](#).

### *Survey Administration and Eligibility*

An exemption for this work was obtained from the University of California Los Angeles Institutional Review Board due to anticipated low risk for study participants. Eligible participants were women with a history of uni- or bilateral mastectomy for treatment of breast cancer or elevated breast cancer risk who were without breast mound reconstruction at the time of survey administration. Patients with a history of breast mound reconstruction that was removed before the survey also were eligible. Three questions were used to screen for eligibility, and patients not meeting these criteria were disqualified and not permitted to complete the remainder of the survey.

The survey was posted online via personal blog, Facebook, and Twitter during a 7-day period: October 15 through 21, 2019. Leaders in several online breast cancer and Going Flat communities were encouraged to participate and share the survey with their followers and community members. Participation was voluntary, and no financial or other type of incentive was provided. The survey tool (Qualtrics) was configured to be anonymous, and personally identifying information was not collected. Repeat surveys from the same Internet protocol address were not allowed.

### *Measures*

Satisfaction with results was determined by responses to three statements. Each respondent was asked to “indicate the extent to which you agree or disagree” with these statements: “I am pleased with the appearance of my chest”; “I feel confident about my body”; and “overall, I am satisfied with my surgical outcome.” Overall satisfaction with surgical results was assessed by a 5-level Likert scale derived from the responses to these statements. A higher score indicated greater satisfaction with surgical results.

The experience of flat denial was measured using a second 5-level Likert scale derived from three statements related to preoperative counseling about the option to go flat and whether respondents felt their surgeon supported their decision to go flat: “my doctor performed the surgery we agreed upon”; “my doctor offered me the option to go flat”; and “my doctor was supportive of me going flat.” On this scale, a lower score was associated with a greater experience of flat denial.

Motivations for going flat were considered among 11 possible reasons identified by our focus group. Respondents were first asked to select all the items that contributed to their decision and then to select the two reasons that most heavily influenced their decision to forgo reconstruction.

We considered several demographic, clinical, and procedure-related details as independent variables based on the items we considered relevant to patient satisfaction with surgical results. The demographic variables were age, sex, gender, race, body mass index (BMI, calculated with height and weight survey responses), bra cup size before mastectomy, insurance at the time of mastectomy, and marital status. The clinical characteristics included indication for mastectomy, uni or bilateral mastectomy, first choice of surgery (i.e., MA vs breast conservation or IBR), history of previous breast mound reconstruction, and receipt of radiation therapy or chemotherapy. The mastectomy procedure variables included year of mastectomy, country, and U.S. state where the mastectomy was

performed, and mastectomy surgeon characteristics including sex of the surgeon and scope of practice. For the patients who initially had breast mound reconstruction, type of reconstruction and reason for reconstruction removal were collected.

### Statistical Analysis

Patient characteristics and survey responses were described using mean  $\pm$  standard deviation or percentage according to the data type. Logistic regression was used to examine demographics and survey characteristics with odds of dissatisfaction (using constructed averaged variable  $< 3$  vs  $\geq 3$  as the reference) in uni- and multivariable models. Frequencies of question responses related to surgery satisfaction and experience with flat denial were summarized using bar plots. Odds of flat denial with the surgeon being male or female and the surgeon having a breast specialty versus other specialty were evaluated with logistic regression. The respondent reasons for going flat also were summarized using a bar plot. A *p* value lower than 0.05 was considered statistically significant. All statistical analyses used STATA MP, version 13.1 (Stata Corp, College Station, TX, USA).

## RESULTS

Of 1097 respondents who initiated the survey, 931 met the eligibility criteria and had complete information for analysis. The study diagram is provided in Appendix Fig. 4.

Table 1 presents the demographic and treatment characteristics of the study population. All the respondents were women. Gender identity was “gender non-binary or non-conforming” for nine patients. One patient identified as a male. The average age of the survey respondents was 49 years (range, 25–85 years). Most of the respondents identified as white (94%) and had private insurance (71%). The mastectomy procedures were performed mainly in the United States, (79%), but 22 countries were represented.

The reasons for mastectomy were unilateral cancer for 78.8%, bilateral cancer for 15.1%, and prophylaxis for 6.1% of the survey respondents. Among the respondents, 19.7% underwent unilateral mastectomy, and 80.3% had bilateral mastectomy. Altogether, 139 respondents (14.9%) initially had breast mound reconstruction that was subsequently removed. Within this subset, tissue expander or direct-to-implant reconstruction was performed for 130 patients (93.5%), whereas 9 patients (6.5%) had an autologous flap or a combination of implant and autologous flap. Among the patients with a prior IBR, the most common

**TABLE 1** Demographic and clinical characteristics of the study participants

Characteristic	n (%)
No. of respondents	931
<i>Sex</i>	
Female	931 (100)
Male	0
Mean age (years)	49 $\pm$ 10
<i>Race</i>	
White	879 (94.4)
Hispanic	16 (1.7)
African American	11 (1.2)
Other	25 (2.7)
Mean BMI ( $\text{kg}/\text{m}^2$ )	28 $\pm$ 6
<i>Bra size<sup>a</sup></i>	
A/AA/B	317 (34.0)
C/D	368 (39.5)
>D	246 (26.4)
<i>Marital status</i>	
Married/long-term relationship	728 (78.2)
Divorced/widowed/single	203 (21.8)
<i>Insurance</i>	
Medicaid	42 (4.5)
Medicare ( $\pm$ secondary)	92 (9.9)
National health service	135 (14.5)
Private insurance	662 (71.1)
<i>Radiation treatment</i>	
Yes	436 (46.8)
No	495 (53.2)
<i>Chemotherapy</i>	
Yes	500 (53.7)
No	431 (46.3)
<i>Country where surgery was performed<sup>a</sup></i>	
United States	734 (78.8)
Canada	75 (8.1)
Great Britain	73 (7.8)
Australia	16 (1.7)
Other	33 (3.5)
<i>U.S. region where surgery was performed</i>	
Northeast	120 (12.9)
Midwest	170 (18.3)
Southeast	222 (23.8)
West	222 (23.8)
Non-U.S.	197 (21.2)
<i>Year surgery was performed</i>	
2005 or earlier	44 (4.7)
2006–2009	43 (4.6)
2010–2015	228 (24.5)
2016–2019	616 (66.2)

**TABLE 1** continued

Characteristic	n (%)
<i>First mastectomy</i>	
Yes	724 (77.8)
No	207 (22.2)
<i>Prior breast mound reconstruction</i>	
Yes	139 (14.9)
No	792 (85.1)
<i>Indication for mastectomy<sup>a</sup></i>	
Prophylaxis	57 (6.1)
Unilateral cancer	733 (78.7)
Bilateral cancer	141 (15.1)
<i>Current mastectomy state</i>	
Unilateral	183 (19.7)
Bilateral	748 (80.3)
<i>Patient-reported surgeon sex<sup>a</sup></i>	
Female	463 (49.7)
Male	465 (49.9)
I don't remember	3 (0.3)
<i>Patient-reported surgeon specialty</i>	
Breast surgeon (breast only)	503 (54.0)
General surgeon	242 (26.0)
Plastic surgeon	165 (17.7)
I don't remember	21 (2.3)
<i>BMI</i> body mass index	

<sup>a</sup>Percentages do not add up to 100% due to rounding

reason for breast mound removal was a problem with the implant (pain, rupture, or other problems), reported by 69.1% (96/139) of the respondents.

Overall, 73.7% of the respondents said MA was their first choice for surgery. The remainder desired breast conservation or mastectomy with some form of breast mound reconstruction, but either they were not candidates for BCS or IBR or the procedures were not successful. Two-thirds of the respondents (65.2%) felt they received adequate information about surgical options so that they could make the right decision, and 20.7% felt that their surgeon did not respect or support their decision to go flat.

Figure 1 depicts the respondent answers to the 5-level Likert-scale questions regarding satisfaction after surgery. The mean scaled score for satisfaction with surgical outcome was  $3.72 \pm 1.17$ , with a Cronbach alpha of 0.8600 indicating high internal consistency. Table 2 reports odd ratios (ORs) for factors associated with dissatisfaction (scaled satisfaction score < 3). In the multivariate analysis, low level of surgeon support for the decision to go flat or flat denial was the strongest predictor of a satisfaction score lower than 3 (OR, 3.85; 95% confidence interval [CI], 2.59–5.72;  $p < 0.001$ ).

Lower satisfaction also was more likely to be reported by respondents with a BMI of  $30 \text{ kg/m}^2$  or higher (OR, 2.74; 95% CI, 1.76–4.27;  $p < 0.001$ ) and those undergoing a unilateral (vs bilateral) procedure (OR, 1.99; 95% CI, 1.29–3.09;  $p = 0.002$ ). The patients less likely to be dissatisfied were those who reported that they had received adequate information about surgical options (OR, 0.48; 95% CI, 0.32–0.69;  $p < 0.0001$ ) and those reporting that they had a surgeon with an exclusive breast surgical practice (OR, 0.56; 95% CI, 0.38–0.81;  $p = 0.002$ ).

Figure 2 depicts the answers of the respondents to the 5-level Likert-scale questions about preoperative counseling and surgeon support of the decision to go flat. The mean scaled score for flat denial was  $3.81 \pm 1.18$ , with a Cronbach alpha of 0.7616 indicating internal consistency. Of the respondents, 22.2% (207/931) had a high level of flat denial (score < 3). In the logistic regression, a flat denial was less likely to be experienced by the patients who had a female (vs male) surgeon (OR, 0.59; 95% CI, 0.44–0.82;  $p = 0.001$  and those who had a surgeon with an exclusive breast surgical practice (OR, 0.48; 95% CI, 0.35–0.66;  $p \leq 0.0001$ ).

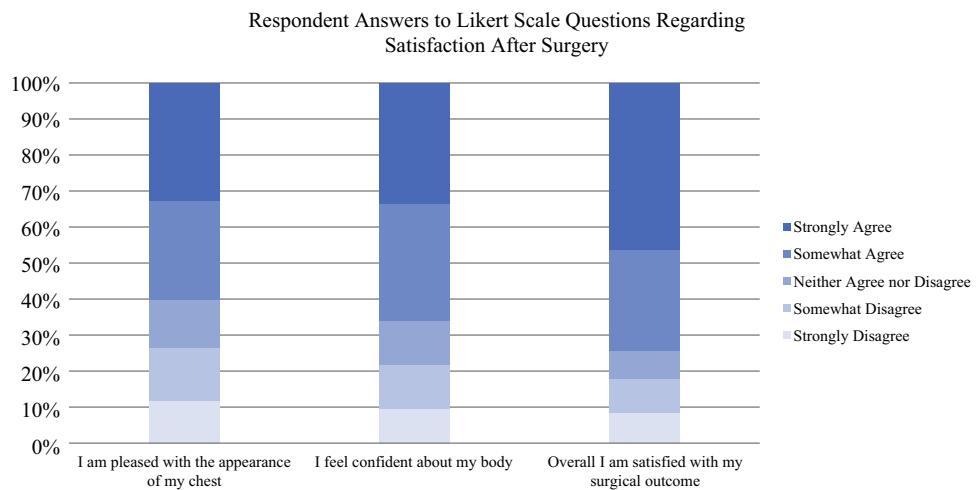
Motivations for going flat are described in Fig. 3. Desire to avoid a foreign body, lower health risks, and lower complication rates were considerations for at least 70% of survey respondents. When asked to describe their top two reasons for forgoing reconstruction, avoidance of a foreign body was selected by 39.9% of respondents, followed by a lower complication rate (34.9%). Very few patients noted direct costs (6.4%) or indirect costs (8%) as factors. Half of the patients (51.1%) reported that they did not think their breasts were important for body image, and 22.7% of all the respondents ranked this reason among the top two considerations for going flat.

## DISCUSSION

The study found that among the 931 participants surveyed in online Going Flat communities, 74.1% were satisfied with their surgical results. However, 22.2% experienced a high level of flat denial, and a high score on the scale for flat denial was the strongest predictor of dissatisfaction with the surgical outcome. Satisfaction with surgical outcome was associated with having adequate preoperative information to make an informed decision and having a surgeon who specialized in breast surgery.

Whereas our study found that patients who elected to go flat were generally satisfied with their outcome, this finding contrasts with those from other reports. Studies using BREAST-Q, a validated survey tool, have reported lower quality-of-life scores for patients after MA than after IBR or BCS<sup>1,8</sup>. The BREAST-Q, which has been validated for

**FIG. 1** Overall satisfaction after surgery



MA patients<sup>24,25</sup>, was considered for our study. However, patient advocates in our focus group were unanimous in their opinion that the questions were biased toward reconstruction. In particular, they were troubled by questions in the mastectomy module such as those asking “how comfortably bras fit,” those starting “with breast area in mind,” and questions about feeling “like other women.” Women whose first choice is to go flat may be more likely to score low on these items simply because the questions do not apply to their situation. This point is perhaps corroborated by studies evaluating patient satisfaction after MA that did not use the BREAST-Q. Such studies were more likely to find that these patients were satisfied with their outcomes<sup>11–13</sup>.

Flat denial was a common and salient concern identified during our focus group discussions. It reflects the degree to which patients felt unsupported by their surgeon in their decision to forgo reconstruction or experienced outcomes different from what they agreed to preoperatively (e.g., a flat chest wall). On our flat denial scale, 22% of the respondents scored lower than 3, indicating a high degree of flat denial. This finding is consistent with prior work<sup>22</sup>.

Our study found that a high level of flat denial was the strongest predictor of dissatisfaction with surgical outcome. Surgeons should become aware of this communication point given the important negative consequences. The respondents were offered the opportunity to comment freely at the conclusion of the survey, and many commented on their experience with flat denial. The examples included the following: “I was never given the choice of going flat; it was like I was ‘expected’ to have reconstruction...” and “I stated multiple times that I intended to stay flat... after surgery they told me they left extra skin in case I changed my mind.”

It is interesting to consider why surgeons may hesitate to recommend mastectomy without reconstruction. Perhaps an unintended consequence of accreditation standards and legislation set forth to ensure that surgeons provide access to reconstruction<sup>17,18</sup> may be that it biases surgeons toward this approach and creates discomfort when their patients choose to go flat. In addition, surgeons may be less confident that they can provide a cosmetically acceptable result for patients who desire a flat chest wall. In the current study, 27% of the patients were not satisfied with the appearance of their chest wall. Achieving a cosmetically acceptable flat chest wall after MA requires attention to specific techniques to prevent lateral dog ears and to avoid excess skin on the chest wall<sup>26–29</sup>. It is important for the surgeon to be familiar with a variety of techniques and to consider collaboration with plastic and reconstructive surgical colleagues because different solutions may better suit specific body types.

We found that patients were more satisfied with their surgical outcome when they reported that a surgeon who specialized in breast surgery had performed the operation. Our study relied on the respondent’s perception of the scope of her surgeon’s practice, but the actual scope of practice cannot be verified. Thus, the patients who perceived that their surgeon was specialized in breast surgery (whether he or she was or not) may have been biased toward higher satisfaction scores. However, other studies have demonstrated improved satisfaction among patients after procedures performed by a surgeon with special training in breast surgery or surgical oncology<sup>30,31</sup>. Consistent with prior work, the top motivations for not pursuing reconstruction were concerns regarding placement of a foreign body and performance of additional procedures, as well as the belief that reconstruction was not important<sup>15</sup>.

**TABLE 2** Uni- and multivariable logistic regression showing the odds of dissatisfaction with overall outcome

Variable	Dissatisfaction with overall outcome: Likert score < 3 vs ≥ 3 (reference)	Univariate		Multivariate	
		OR (95% CI)	p Value	OR (95% CI)	p Value
Age		1.01 (0.99–1.02)	0.370	1.01 (0.99–1.03)	0.161
<i>Race</i>					
White vs other (ref)		1.17 (0.59–2.32)	0.652	1.18 (0.54–2.58)	0.680
<i>BMI</i>					
<25		Reference		Reference	
25–30		1.38 (0.93–2.04)	0.105	1.56 (1.00–2.42)	<b>0.049</b>
≥30		2.73 (1.88–4.03)	< <b>0.0001</b>	2.74 (1.76–4.27)	< <b>0.0001</b>
<i>Bra size</i>					
A–B		Reference		Reference	
C–D		1.92 (1.32–2.80)	<b>0.001</b>	1.39 (0.90–2.14)	0.137
>D		2.12 (1.41–3.18)	< <b>0.0001</b>	1.50 (0.92–2.43)	0.100
<i>Indication for mastectomy</i>					
Prophylaxis vs cancer (ref)		0.82 (0.40–1.66)	0.574	0.91 (0.41–2.05)	0.828
<i>Country where surgery was performed</i>					
U.S. vs other (ref)		1.34 (0.91–1.97)	0.144	1.38 (0.87–2.17)	0.169
<i>First choice of surgery</i>					
Going flat vs reconstruction (ref)		0.42 (0.30–0.58)	< <b>0.0001</b>	0.63 (0.40–0.99)	<b>0.049</b>
<i>Current state</i>					
Unilateral versus Bilateral (ref)		1.18 (0.82–1.71)	0.377	1.99 (1.29–3.09)	<b>0.002</b>
<i>Surgeon</i>					
Breast surgeon vs other (ref)		0.45 (0.33–0.61)	< <b>0.0001</b>	0.56 (0.38–0.81)	<b>0.002</b>
Breast mound reconstruction					
No reconstruction vs reconstruction (ref)		0.312 (0.21–0.45)	< <b>0.0001</b>	0.79 (0.45–1.42)	0.445
<i>Adequate information</i>					
Yes versus No (ref)		0.28 (0.20–0.38)	< <b>0.0001</b>	0.48 (0.32–0.69)	< <b>0.0001</b>
<i>Surgeon supported going flat</i>					
No vs Yes (ref)		5.32 (3.77–7.49)	< <b>0.0001</b>	3.85 (2.59–5.72)	< <b>0.0001</b>
<i>Radiation therapy</i>					
Yes vs no (ref)		0.94 (0.70–1.27)	0.699	0.87 (0.59–1.28)	0.470
<i>Chemotherapy</i>					
Yes vs no (ref)		1.06 (0.78–1.43)	0.721	1.19 (0.81–1.78)	0.367

OR odds ratio; CI confidence interval; BMI body mass index

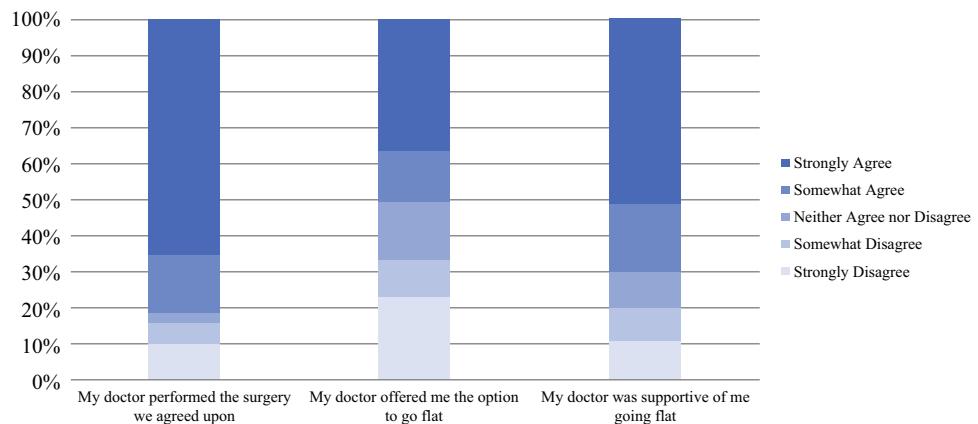
In a recent survey assessing patient perspectives on reconstruction decision-making, fears related to implants were reported by 36% of the patients who had undergone MA<sup>15</sup>. Such fears may become more common in light of the U.S. Food and Drug Administration's recall of specific textured breast implants and increased awareness of breast implant-associated anaplastic large-cell lymphoma as well as other implant-associated conditions<sup>32</sup>. In addition, findings have shown that satisfaction with implant reconstruction declines over time. In a prospective, multicenter study of patients undergoing IBR between 2012 and 2015, those who underwent implant reconstruction reported

declining physical and sexual well-being during the study period (according to BREAST-Q scores), in contrast to patients who received autologous reconstruction<sup>33</sup>.

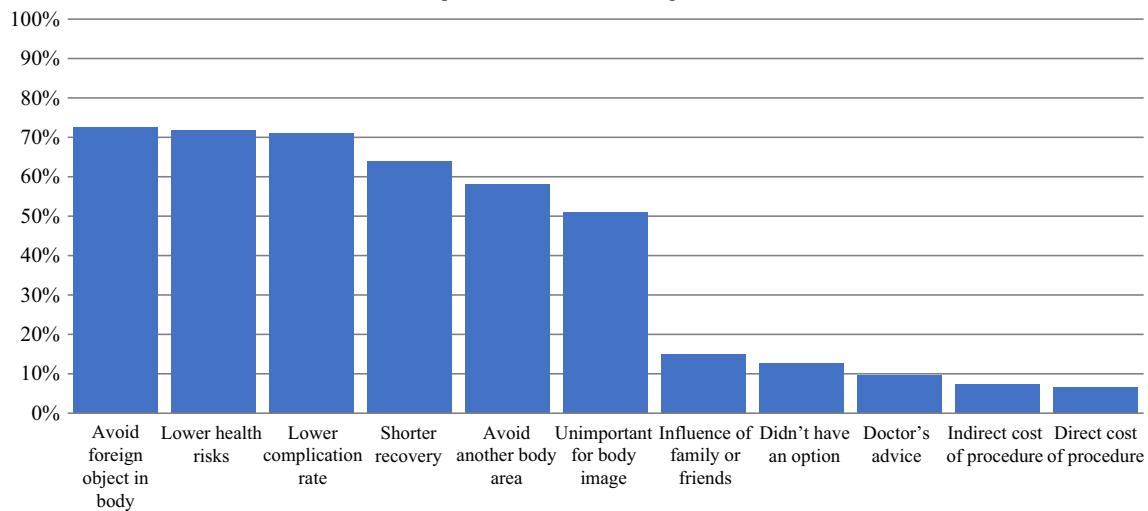
Our study had limitations inherent to surveys of an anonymous social media patient population. The identities of the respondents could not be verified, and we relied on self-reported clinical and treatment factors. The respondents were active in online Going Flat communities and self-selected for survey participation, which could have biased the results. Surveys of patients active on social media tend to capture a relatively homogeneous population that is predominantly white, well-educated, and of higher socioeconomic status<sup>34–36</sup>.

**FIG. 2** Respondent experiences with flat denial

Respondent Answers to Likert Scale Questions Regarding Experience with Flat Denial



Respondent Reasons for Going Flat

**FIG. 3** Respondent reasons for going flat

Our cohort was 94.4% white and relatively young. The majority of the cohort had private insurance, perhaps making our findings inapplicable to a more diverse population. In particular, women who previously have been shown to have lower reconstruction rates, including those in racial or ethnic minority groups, older women, and those without private insurance<sup>37</sup>, were underrepresented in our study population. This reflects the targeting of our study toward a unique patient population and is meant to broaden surgeon awareness of how this growing community can be better supported. In addition, in our study population of patients thought to have knowledge of reconstruction and access to the procedure, we found

satisfaction with MA to be higher than other studies have reported, and we offer insight into correlates of dissatisfaction in this group.

Several strengths of our study deserve consideration. We report on the experience of many patients who underwent MA. Most of the respondents had their surgery within the past 5 years, which may have reduced recall bias regarding their initial surgical recommendations and experience. We did not use a validated survey, but our study is the first to use a tool specifically designed with input from patient advocates to measure correlates of satisfaction in the unreconstructed population, and we identified concerns unique to these patients not captured by other validated surveys.

## CONCLUSIONS

In our survey of online Going Flat communities, the majority of patients undergoing mastectomy without reconstruction were satisfied with their surgical outcome, illustrating that forgoing breast mound reconstruction after mastectomy is a valid option for women pursuing surgery for breast cancer or management of breast cancer risk. However, at least 20% of patients felt that their surgeon did not support their decision to forgo reconstruction, and a high level of flat denial was strongly related to dissatisfaction with outcome. Our findings show a need for additional study and validated tools to use for optimal counsel and support of women not interested in breast mound reconstruction.

**ACKNOWLEDGMENT** The authors thank the following patient advocates for their assistance with survey development and pre-distribution review as well as with dissemination of the survey: Kimberly Bowles, Catherine Guthrie, AnneMarie Mercurio, and Alicia Staley. We also thank everyone who shared and participated in the survey.

**DISCLOSURE** There are no conflicts of interest.

## APPENDIX

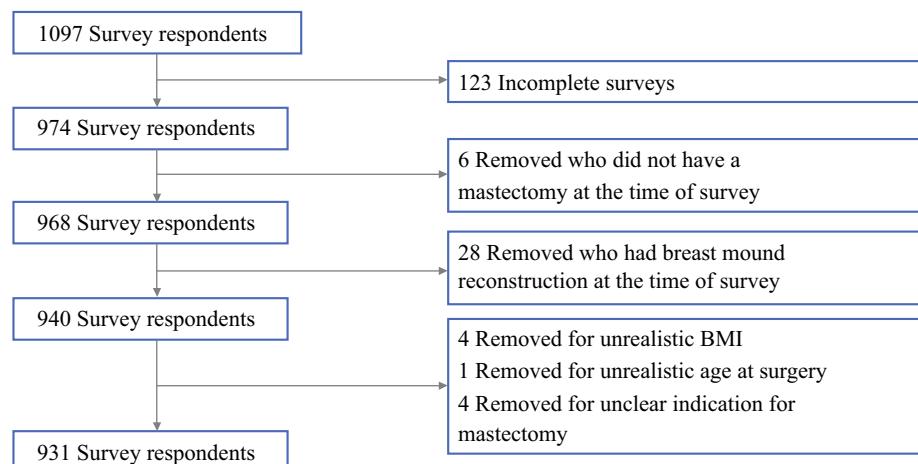
### *Survey questionnaire*

We thank you for taking the time to participate in this survey. Please review the questions carefully and answer as best possible (Fig. 4).

**“Going Flat”** refers to mastectomy (breast removal) **without** breast mound reconstruction, one side or both sides

**Breast mound reconstruction** refers to procedures that aim to **completely “rebuild”** after mastectomy to give the appearance of a pre-surgical breast, not just fill in areas on an otherwise flat chest

**FIG. 4** Cohort construction



1. Did you have a mastectomy (removal of one or both breasts)?
  - Yes
  - No  $\geq$  disqualified
2. Did you have breast mound reconstructive surgery **at the time of or after** mastectomy (one side or both sides)?
  - I had breast mound reconstruction and I still have the reconstruction  $\geq$  disqualified
  - I had breast mound reconstruction, but then I **decided to have** the reconstruction removed: skip to Q3
  - I had breast mound reconstruction, but then I **had to have** the reconstruction removed: skip to Q3
  - I did not have breast mound reconstruction: skip to Q5
3. If you had **breast mound reconstruction** at the time of or after your mastectomy surgery (even if the reconstruction has been removed), what type did you have? Please read the choices carefully and choose the one that best fits your situation:
  - Tissue expander with eventual implant placement or plan for implant placement
  - Direct to implant (no tissue expander)
  - Flap using your own body fat and/or muscle including DIEP, TRAM, latissimus flap and other
  - Combination of tissue expander/implant + flap
  - Fat injections only
  - “Goldilocks” using only skin
4. Why did you decide to go flat after reconstruction? Please check all that apply:
  - Problem with implant: pain, rupture, or other problems

- Development of implant-associated cancer or other illness
- Concern of implant-associated cancer or other illness
- Problem with fat/muscle flap, such as pain
- Loss of fat/muscle flap (also known as flap failure) due to infection, poor blood supply, or other problems
- Not happy with appearance of reconstruction

5. Which scenario best fits your situation?

- Mastectomy was my first operation *≥skip to question 7*
- I had one or more lumpectomy surgeries for treatment of cancer before my mastectomy (lumpectomy may also be referred to as partial mastectomy, surgical biopsy, or excisional biopsy).

6. If you initially had lumpectomy (also known as partial mastectomy or surgical biopsy or excisional biopsy) as your first surgery, why did you have a mastectomy? Please read the choices carefully and choose the one that best fits your situation:

- Positive margins or could not get clear margins
- Did not like the appearance after lumpectomy
- Did not want to do radiation
- Had radiation before and could not do it again
- Other, please specify

7. Please select the best description of *why* you had mastectomy surgery. Please read the choices carefully and choose the one that best fits your situation:

- I did not have cancer. Surgery was performed as preventative/prophylactic due to genetic mutation, high risk, or family history
- I had cancer (may include stage 0/DCIS) in one breast
- I had cancer (may include stage 0/DCIS) in both breasts (either at the same or at different points in time)
- Gender confirmation (female to male or female to neutral transition)
- Other, please specify

8. Please read the options carefully and choose the one that best fits your situation. Please report on your current state, even if you had the surgeries at different times:

- Single—one side removed for cancer
- Double—one side removed for cancer and the other for prophylaxis/prevention

- Double—both sides removed for cancer
- Double—both sides removed for prophylaxis/prevention

9. Regarding the discussions with your surgeon about your options for surgery, please check **all of the choices** that your surgeon presented to you:

- Breast conservation (lumpectomy, partial mastectomy, excisional biopsy, surgical biopsy)
- Mastectomy without breast mound reconstruction (going flat)
- Mastectomy with breast mound reconstruction using a tissue expander and/or implant
- Mastectomy with breast mound reconstruction using muscle and/or fat from your own body including DIEP, TRAM, latissimus flap, and other)
- Mastectomy with breast mound reconstruction using a combination of implant and flap

10. What was **your** first choice for surgery?

- Breast conservation (lumpectomy, partial mastectomy, excisional biopsy, surgical biopsy)
- Mastectomy without breast mound reconstruction (going flat)
- Mastectomy with breast mound reconstruction using a tissue expander and/or implant
- Mastectomy with breast mound reconstruction using muscle and/or fat from your own body including DIEP, TRAM, latissimus flap, and other)
- Mastectomy with breast mound reconstruction using a combination of implant and flap
- Other, please specify

11. Do you feel you had adequate information about all of your surgical options so that you could make the right decision for you?

- Yes
- No

12. Please describe your reasons for going flat. Please check all that apply:

- Shorter recovery
- Direct cost of procedure. An example of a **direct cost** is medical bills and co-pays for the procedure.
- Indirect cost of procedure. An example of **indirect cost** is lost wages due to time off work
- Lower complication rate
- Lower health risks
- Breasts are not important for my body image

- Don't want procedure on another body area (abdominal flap, etc.)—not related to cost
  - Don't want a foreign object in my body (tissue expander or implant)—not related to cost
  - Influence of family, friends, or other source, or knowledge of others' experience with reconstruction or going flat
  - Doctor's advice or recommendation
  - Didn't have an option—reconstruction didn't work, or I couldn't have reconstruction
13. Of the list above, what are your top two reasons for going flat:
14. Do you feel your surgeon respected and supported your decision to "go flat"?
- Yes
  - No
15. During a mastectomy surgery, the breast is removed, and the skin is closed. Usually the same surgeon does both parts of the procedure. In your situation, which of the following best describes the surgeon who did the skin closure for the going flat procedure?
- Breast surgeon (only performs breast surgery)
  - General surgeon (performs breast and other body area surgeries)
  - Plastic/reconstructive surgeon
  - I don't know or don't remember
16. Was the surgeon who performed the skin closure for the flat procedure female or male?
- Year entry
18. How old were you when you had your mastectomy surgery? If you had more than one mastectomy surgery, please indicate your age at the first procedure:
19. Did you have any additional surgery to revise or redo the scar area?
- Yes
  - No ≥ skip to Q 21
- 20 Who performed the additional surgery to revise the scar area?
- Same surgeon who did my initial mastectomy (breast surgeon)
  - Same surgeon who did my initial mastectomy (general surgeon)
  - Same plastic/reconstructive surgeon who did the initial skin closure
  - Different breast surgeon
  - Different general surgeon
  - Different plastic/reconstructive surgeon
  - I don't know or don't remember
21. Did the final results of the surgery (appearance of the chest area) match your expectations?
- Yes
  - No
22. For each of the statements below regarding satisfaction after surgery, please indicate the extent to which you agree or disagree:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
My doctor performed the surgery we agreed upon					
My doctor offered me the option to go flat					
My doctor was supportive of me going flat					
The recovery time from surgery matched my expectations					
I did not have any surgical complications					
I am pleased with the appearance of my chest					
I feel confident about my body					
Overall, I am satisfied with my surgical outcome					

- Female
  - Male
  - I don't remember
17. What year did you have your mastectomy surgery? If you do not remember exactly, please use your best estimate:
23. Have you had radiation therapy to the breast or chest, **on the side of mastectomy**? Please read the choices carefully and choose the one that best fits your situation:
- I had radiation **before** my mastectomy **for previous breast cancer**

- I had radiation **after** my mastectomy **due to breast cancer**
  - I had radiation for Hodgkin's lymphoma or other medical condition **before my mastectomy**
  - I had radiation for Hodgkin's lymphoma or other medical condition **after my mastectomy**
  - I have not had radiation to the breast or chest
24. Did you receive **chemotherapy**? Please **do not consider endocrine therapy** such as tamoxifen or aromatase inhibitors (anastrozole/arimidex, letrozole/femara, exemestane/aromasin) in answering this question. Please read the choices carefully and choose the one that best fits your situation:
- I received chemotherapy **before** my mastectomy surgery, **for previous breast or non-breast cancer**
  - I received chemotherapy **before** my mastectomy surgery, **for my current breast cancer**
  - I received chemotherapy **after** my mastectomy surgery, **for my current breast cancer**
  - I received chemotherapy **after** my mastectomy surgery, **for non-breast cancer**
  - I have not received chemotherapy
25. What was your original (before surgery) bra cup size? Please choose the most appropriate size:
- A/AA cup
  - B cup
  - C or D cup
  - DD through E cup
  - F cup or larger
26. How much do you weigh in pounds? If you measure your weight in kilograms or stone, please use this calculator to convert to pounds:
- <https://www.thecalculatorsite.com/conversions/common/kg-to-stones-pounds.php>
27. What is your height in feet and inches? Please enter numbers only. If you measure your height in meters, please use this calculator to convert to feet and inches:
- <https://www.thecalculatorsite.com/conversions/common/meters-to-feet-inches.php>
28. How old are you?
29. What is your marital or relationship status?
- Single, never married
  - Married
  - Long-term relationship
  - Divorced or separated
  - Widowed
30. What is the highest level of education or degree that you received?
- Did not attend high school
  - Attended some high school but did not receive a degree
  - High school or graduate equivalency degree (GED)
  - Some college but no degree
  - Associate degree
  - Bachelor degree
  - Graduate degree
31. In what country was your surgery performed?
- Dropdown menu of all countries
  - If answer is U.S., go to Q32
  - If answer is non-U.S. country: skip to Q33
32. In what state was your surgery performed?  
Dropdown menu of U.S. states
33. What best describes your racial/ethnic background?
- American Indian or Alaska native
  - Asian
  - Black or African American
  - Hispanic, Latino or Spanish origin
  - Native Hawaiian or Pacific Islander
  - White
  - Other, please specify
34. What type of insurance did you have at the time of your mastectomy surgery?
- Private insurance–individual policy, not from employer
  - Private insurance–group policy from employer
  - Medicare with or without a secondary insurance
  - Medicaid
  - National Health Service
  - I don't know or I don't remember
35. What is your sex (please list sex at birth):
- Female
  - Male
- The following questions are optional:
36. Please list the gender with which you best identify:
- Female
  - Male
  - Gender variant/non-binary/nonconforming
  - Decline to state
37. Please enter any other comments you might have for the research team:

Thank you for your time and participation! We value your opinions.

## REFERENCES

1. Atisha DM, Rushing CN, Samsa GP et al. A national snapshot of satisfaction with breast cancer procedures. *Ann Surg Oncol.* 2015;22:361–9.
2. Fisher B, Anderson S, Bryant J, et al. Twenty-year follow-up of a randomized trial comparing total mastectomy, lumpectomy, and lumpectomy plus irradiation for the treatment of invasive breast cancer. *N Engl J Med.* 2002;347(16):1233–1241.
3. Jaggi R, Li Y, Morrow M, et al. Patient-reported quality of life and satisfaction with cosmetic outcomes after breast conservation and mastectomy with and without reconstruction: results of a survey of breast cancer survivors. *Ann Surg.* 2015;261:1198–206.
4. Kruper L, Holt A, Xu XX, et al. Disparities in reconstruction rates after mastectomy: patterns of care and factors associated with the use of breast reconstruction in Southern California. *Ann Surg Oncol.* 2011;18:2158–65.
5. Veronesi U, Cascinelli N, Mariani L, et al. Twenty-year follow-up of a randomized study comparing breast-conserving surgery with radical mastectomy for early breast cancer. *N Engl J Med.* 2002;347:1227–32.
6. Kummerow KL, Du L, Penson DF, Shyr Y, Hooks MA. Nationwide trends in mastectomy for early-stage breast cancer. *JAMA Surg.* 2015;150:9–16.
7. Tan MP, Silva E. Addressing the paradox of increasing mastectomy rates in an era de-escalation of therapy: communication strategies. *Breast.* 2018;38:136–43.
8. Eltahir Y, Werners LLCH, Dreise MM, et al. Quality-of-life outcomes between mastectomy alone and breast reconstruction: comparison of patient-reported BREAST-Q and other health-related quality-of-life measures. *Plast Reconstr Surg.* 2013;132:201e–9e.
9. Howes BHL, Watson DI, Xu C, Fosh B, Canepa M, Dean NR. Quality of life following total mastectomy with and without reconstruction versus breast-conserving surgery for breast cancer: a case-controlled cohort study. *J Plast Reconstr Aesthet Surg.* 2016;69:1184–91.
10. Retrouvey H, Kerrebijn I, Metcalfe KA, et al. Psychosocial functioning in women with early breast cancer treated with breast surgery with or without immediate breast reconstruction. *Ann Surg Oncol.* 2019;26:2444–51.
11. Collins KK, Liu Y, Schootman M, et al. Effects of breast cancer surgery and surgical side effects on body image over time. *Breast Cancer Res Treat.* 2011;126:167–76.
12. Frost MH, Hoskin TL, Hartmann LC, Degnim AC, Johnson JL, Boughey JC. Contralateral prophylactic mastectomy: long-term consistency of satisfaction and adverse effects and the significance of informed decision-making, quality of life, and personality traits. *Ann Surg Oncol.* 2011;18:3110–16.
13. Lee C, Sunu C, Pignone M. Patient-reported outcomes of breast reconstruction after mastectomy: a systematic review. *J Am Coll Surg.* 2009;209:123–33.
14. Alderman AK, Hawley ST, Janz NK, et al. Racial and ethnic disparities in the use of postmastectomy breast reconstruction: results from a population-based study. *J Clin Oncol.* 2009;27:5325–30.
15. Morrow M, Li Y, Alderman AK, et al. Access to breast reconstruction after mastectomy and patient perspectives on reconstruction decision-making. *JAMA Surg.* 2014;149:1015–21.
16. Tseng JF, Kronowitz SJ, Sun CC, et al. The effect of ethnicity on immediate reconstruction rates after mastectomy for breast cancer. *Cancer.* 2004;101:1514–23.
17. Kamali P, Ricci JA, Curiel DA, et al. Immediate breast reconstruction among patients with Medicare and private insurance: a matched-cohort analysis. *Plast Reconstr Surg Glob Open.* 2018;6: e: 1552.
18. National Accreditation Program for Breast Centers. 2018 Standards, Standard 2.18, pp. 54–5. Retrieved 11 November 2020 at <https://accreditation.facs.org/accreditationdocuments/NAPBC/Portals/20Resources/2018NAPBCStandardsManual.pdf>.
19. Bowles, KB. Flat closure after mastectomy: are your patients satisfied with the results? *Cancer Res.* 2020;80(4 Suppl). Abstract P6-11-23. <https://doi.org/10.1158/1538-7445.sabcs19-p6-11-23>.
20. La J, Jackson S, Shaw R. “Flat and fabulous”: women’s breast reconstruction refusals post-mastectomy and the negotiation of normative femininity. *J Gender Stud.* 2019;28:603–16. <https://doi.org/10.1108/09589236.2019.1601547>.
21. Rabin RC. “Going Flat” after breast cancer. *The New York Times* 31 October 2016. Retrieved 11 November 2020 at <https://www.nytimes.com/2016/11/01/well/live/going-flat-after-breast-cancer.html> Accessed %20July %202017.
22. Wakeley ME, Bare CF, Pine R, et al. A social media survey of women who do not pursue reconstruction after mastectomy for breast cancer: characterizing the “Going Flat” movement. *Breast J.* 2020. <https://doi.org/10.1111/tbj.13781>.
23. Peters M, Potter CM, Kelly L, et al. The long-term conditions questionnaire: conceptual framework and item development. *Patient Relat Outcome Meas.* 2016;7:109–25.
24. Cano SJ, Klassen AF, Scott AM, Cordeiro PG, Pusic AL. The BREAST-Q: further validation in independent clinical samples. *Plast Reconstr Surg.* 2012;129:293–302.
25. Cohen WA, Mundy LR, Ball TNS, et al. The BREAST-Q in surgical research: a review of the literature 2009–2015. *J Plast Reconstr Aesthet Surg.* 2016;69:149–62.
26. Clough KB, Massey EJD, Mahadev GK, Kaufman GJ, Nos C, Sarfati I. Oncoplastic technique for the elimination of the lateral “dog ear” during mastectomy. *Breast J.* 2012;18:588–90.
27. Djohan M, Knackstedt R, Leavitt T, Djohan R, Grobmyer S. Technical considerations in nonreconstructive mastectomy patients. *Breast J.* 2020;26:702–4.
28. Lim GH, Tan HF. Surgical techniques to avoid lateral dog ear of the mastectomy scar: a systematic review. *Int J Surg.* 2016;26:73–8.
29. Thomas R, Mouat C, King B. Mastectomy flap design: the “waisted teardrop” and a method to reduce the lateral fold. *ANZ J Surg.* 2012;82:329–33.
30. Smith BD, Lei X, Diao K, et al. Effect of surgeon factors on long-term patient-reported outcomes after breast-conserving therapy in older breast cancer survivors. *Ann Surg Oncol.* 2020;27:1013–22.
31. Waljee JF, Hawley S, Alderman AK, Morrow M, Katz SJ. Patient satisfaction with treatment of breast cancer: does surgeon specialization matter? *J Clin Oncol.* 2007;25:3694–8.
32. Coroneos CJ, Selber JC, Offodile AC II, Butler CE, Clemens MS. U.S. FDA breast implant postapproval studies: long-term outcomes in 99,993 patients. *Ann Surg.* 2019;269:30–6.
33. Santosa KB, Qi J, Kim HM, Hamill JB, Wilkins EG, Pusic AL. Long-term patient-reported outcomes in post-mastectomy breast reconstruction. *JAMA Surg.* 2018;153(10):891–9.
34. George GC, Buford A, Hess K, et al. Cancer-related Internet use and online social networking among patients in an early-phase clinical trials clinic at a comprehensive cancer center. *JCO Clin Cancer Inform.* 2018;2:1–14.

35. Greenup RA, Rushing C, Fish L, et al. Financial costs and burden related to decisions for breast cancer surgery. *J Oncol Pract.* 2019;15:e666–76.
36. Magnezi R, Grosberg D, Novikov I, Ziv A, Shani M, Freedman LS. Characteristics of patients seeking health information online via social health networks versus general internet sites: a comparative study. *Inform Health Soc Care.* 2015;40:125–38.
37. Kruper L, Xu XX, Henderson K, Bernstein L, Chen SL. Utilization of mastectomy and reconstruction in the outpatient setting. *Ann Surg Oncol.* 2013;20:828–35.

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