# Long-term Satisfaction and Psychological and Social Function Following Bilateral Prophylactic Mastectomy

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**Context** Prophylactic mastectomy is a preventive option for women who wish to reduce their risk of breast cancer. There has been concern about possible negative psychological sequelae following this procedure. However, few data are available regarding long-term satisfaction and psychological and social function following this procedure.

**Objective** To evaluate patients' long-term satisfaction and psychological and social function following prophylactic mastectomy.

**Design, Setting, and Participants** Descriptive study of all women known to be alive (n=609) who had a family history of breast cancer and elected to undergo bilateral prophylactic mastectomy at a large, tertiary US health care clinic between 1960 and 1993, 94% (n=572) of whom completed a study questionnaire.

**Main Outcome Measures** Satisfaction with procedure and effects on psychological and social function, based on responses to the study-specific questionnaire.

**Results** Mean time from prophylactic mastectomy to last follow-up was 14.5 years. Most women (70%) were satisfied with the procedure; 11% were neutral; and 19% were dissatisfied. Among the psychological and social variables, the most striking finding was that 74% reported a diminished level of emotional concern about developing breast cancer. The majority of women reported no change/favorable effects in levels of emotional stability (68%/23%), level of stress (58%/28%), self-esteem (69%/13%), sexual relationships (73%/4%), and feelings of femininity (67%/8%). Forty-eight percent reported no change in their level of satisfaction with body appearance; 16% reported favorable effects. However, 9%, 14%, 18%, 23%, 25%, and 36% reported negative effects in these 6 variables, respectively.

**Conclusions** This study suggests that positive outcomes following prophylactic mastectomy include decreased emotional concern about developing breast cancer and generally favorable psychological and social outcomes. These must be weighed against the irreversibility of the decision, potential problems with implants and reconstructive surgery, and occurrence of adverse psychological and social outcomes in some women.

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Bilateral prophylactic mastectomy, the preventive removal of breast tissue, is an option for women at high risk for breast cancer. Recent data from the Mayo Clinic showed that the procedure lowers the incidence of breast cancer by approximately 90% among women with a family history of breast cancer.[1] These results underscore the need for data on morbidities associated with prophylactic mastectomy. Specifically, information regarding satisfaction and psychological and social function needs to be assessed to provide women and their physicians the information they need to make appropriate health care decisions.

Prophylactic mastectomy is preferred by a minority of women at high risk for breast cancer. Although 57% of women at high risk reported prophylactic mastectomy as an option to be considered in 1 study,[2] generally fewer respondents (16%-20%) rate prophylactic mastectomy as a favorable option.[3,4] Only 9% to 17% of women who express an interest in prophylactic mastectomy actually proceed with the surgery.[2,4,5]

To our knowledge, there is no literature on the psychological and so-

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cial adjustment of women who have had this procedure and limited data on satisfaction following it. One study of 14 women reported that they were satisfied with their decision to have prophylactic mastectomy at 6 to 30 months after surgery.[2,6] Borgen et al[7] found that 5% of respondents had significant regrets after prophylactic mastectomy.

Important questions remain unanswered. What reasons do women describe for having had prophylactic mastectomy? How does prophylactic mastectomy affect long-term psychological and social function? How satisfied are women with prophylactic mastectomy? What factors are associated with prophylactic mastectomy satisfaction or dissatisfaction for women at high risk? To address these questions, we performed a corollary study of psychosocial and social outcomes, and overall satisfaction, to determine the efficacy of prophylactic mastectomy.[1]

**Table 1.** Demographic and Surgical Variables (N = 572)*

| Variable | Value |
|---|---|
| Current age, mean, y | 57 |
| Age at PM, mean, y | 42 |
| Marital status | |
| Married | 81 |
| Single | 5 |
| Divorced/separated | 8 |
| Widowed | 5 |
| Unknown | 2 |
| Family risk | |
| Moderate | 65 |
| High | 35 |
| No. of breast biopsies, mean | 2.3 |
| Follow-up after PM, mean, y | 14.5 |
| Type of PM | |
| Subcutaneous | |
| With reconstruction | 89 |
| Without reconstruction | 2 |
| Simple | |
| With reconstruction | 6 |
| Without reconstruction | 3 |
| Reconstruction | |
| Type | |
| Implants | 100 |
| TRAM | 0 |
| Timing of reconstruction | |
| After the time of PM | 91 |
| Delayed | 9 |

*PM indicates prophylactic mastectomy; TRAM, transverse rectus abdominal myocutaneous. Values are expressed as percentages unless otherwise indicated.

**Table 2.** Reasons for Prophylactic Mastectomy (N = 572)

| | Rank* | | | |
|---|---|---|---|---|
| Reason | 1 | 2 | 3 | Total |
| Family history | 38 | 22 | 8 | 68 |
| Physician's advice | 20 | 22 | 30 | 72 |
| Nodular breasts | 18 | 27 | 24 | 69 |
| Worrisome biopsies | 9 | 9 | 3 | 21 |
| Psychological/ emotional concerns | 3 | 9 | 10 | 22 |

*Participants were asked to rank their top 3 reasons for electing prophylactic mastectomy in order of importance. Values are expressed as percentages.

## METHODS

### Sample

A total of 639 cancer-free women with a family history of breast cancer had bilateral prophylactic mastectomy at the Mayo Clinic between 1960 and 1993. These women were categorized into high-risk (n=214) or moderate-risk (n=425) groups based on the extent of their family history. Women in the high-risk group had a pedigree consistent with a single-gene, autosomal dominant predisposition to breast cancer. Women who did not meet these criteria were considered to be at moderate risk. Further details of the identification and characterization of the study population, as well as inclusion and exclusion criteria, have been previously reported.[1]

### Questionnaire

Initial questionnaires were followed up by additional mailings and telephone calls if there was no response. Women who indicated they were unwilling to participate were not contacted further.

Our study-specific questionnaire used single-item ordinal measurement scales to identify reasons for choosing prophylactic mastectomy (such as family history of breast cancer, lumpy breasts, psychological or emotional, worrisome findings on biopsy, physician's advice, other), satisfaction with prophylactic mastectomy, and choice to have prophylactic mastectomy again. We asked women to rank their top 3 reasons for choosing prophylactic mastectomy. Additionally, we used single-item ordinal scales to measure the effects of prophylactic mastectomy on 7 psychological and social variables including self-esteem, body appearance, feelings of femininity, sexual relationships, emotional concern about developing breast cancer, level of stress, emotional stability, as well as perceived risk of breast cancer before and after prophylactic mastectomy. The use of individual items to measure specific aspects of patient quality of life, for which tools are nonexistent and/or nonspecific has been identified as an acceptable practice.[8-11] Open-ended questions solicited participants' basis for their rating of their satisfaction with prophylactic mastectomy and reasons why they would or would not choose to have a prophylactic mastectomy if making that choice again.

Question clarity and inclusiveness as well as face validity were established by a panel of experts consisting of researchers from the fields of medicine, psychology, nursing, and biostatistics who had expertise in the areas of prophylactic mastectomy, questionnaire item development, and/or psychosocial research. The questionnaire was pilot tested on women who had prophylactic mastectomy. Results of the pilot indicated that items were clear and inclusive.

### Data Analysis

We analyzed the data using basic descriptive statistics including frequency distributions, Spearman correlations, cross-tabulations, and $\chi^2$ analyses. Responses to psychological and social function items were collapsed to identify if the effect represented a favorable effect, no change, or an adverse effect on function. Repondents also rated satisfaction and choice to have prophylactic mastectomy on a 5-point scale: very positive, positive, neither, negative, and very negative. Multiple linear regression was used to evaluate the independent contributions of variables to women's satisfaction and their choice to have prophylactic mastectomy again. Independent variables included the 7 psychological and social variables, reasons for choosing prophylactic mastectomy, family history status of moderate or high risk, perceived risk before and after prophylactic mastectomy, marital status, whether reconstructive surgery was done, immediate vs delayed reconstructive surgery, number of surgical com-


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plications after prophylactic mastectomy, problems with implants, age at prophylactic mastectomy, length of time since procedure, and number of prior biopsies. Psychological and social variables were analyzed as interval data when using multiple regression. Differences in psychological and social function and satisfaction based on age and length of time since procedure were examined using correlations and responses by year. For open-ended questions, we coded the themes and concepts of the responses and computed their frequency. We recoded 10% of the questionnaires to determine intrarater reliability ($r$=0.97).

## RESULTS

Of the overall sample of 639 women, 609 were alive at the time of this study and were mailed questionnaires. Ninety-four percent (n=572) of the women participated. Demographic and surgical data are given in TABLE 1.

### Reasons for Prophylactic Mastectomy

Family history of breast cancer was the most common reason cited for prophylactic mastectomy (TABLE 2). Ninety-eight percent of the women gave more than 1 reason for prophylactic mastectomy; 82% noted more than 2 reasons. The most frequent combination of reasons included family history of breast cancer, physician advice, and nodular breasts.

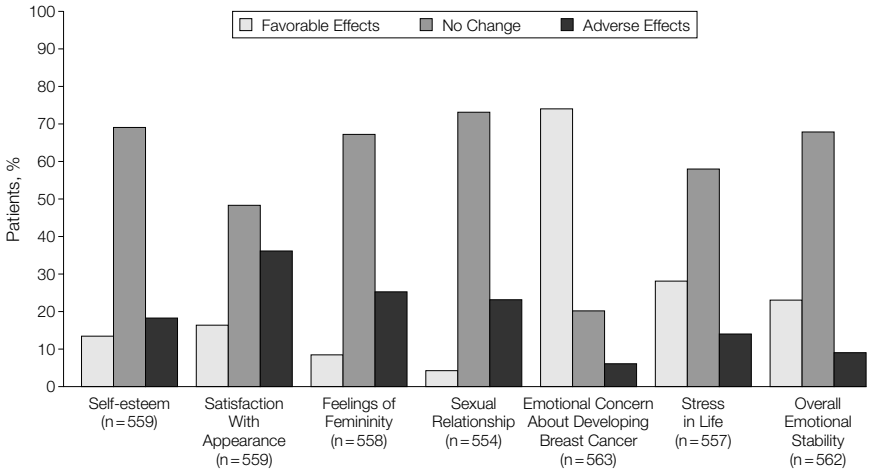
Women with moderate or high risk for breast cancer gave comparable reasons for prophylactic mastectomy with 2 exceptions: (1) more women with high risk than with moderate risk cited family history of breast cancer as a major reason (93% vs 60%, respectively; $P$=.001) and (2) more women with moderate risk than with high risk reported nodular breasts (88% vs 78%, respectively; $P$=.002).

### Psychological and Social Consequences of Prophylactic Mastectomy

Seventy-four percent of women reported a diminished level of emotional concern about developing breast cancer. The majority of women reported no change/favorable effects in level of emotional stability (68%/23%), level of stress (58%/28%), self-esteem (69%/13%), sexual relationships (73%/4%), and feelings of femininity (67%/8%). Forty-eight percent reported no change in their level of satisfaction with appearance; 16% reported favorable effects (FIGURE 1). Responses to psychological and social variables were not significantly associated with age at prophylactic mastectomy, length of follow-up, family history of moderate vs high risk for breast cancer, or whether mastectomy was simple or subcutaneous. Several of the psychological and social variables were, as expected, significantly correlated with each other. The strongest correlations occurred among self-esteem, satisfaction with body appearance, feelings of femininity, and sexual relationships ($r$=0.41-0.62), and emotional concern about developing breast cancer and level of stress ($r$=0.44). Correlations among the other psychological and social variables ranged from 0.02 to 0.25.

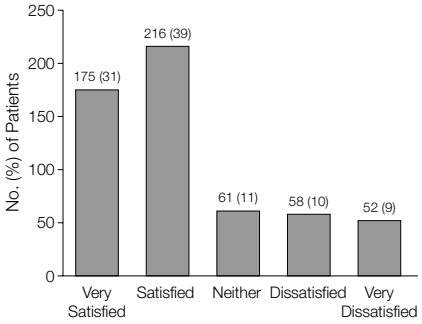
For some women, prophylactic mastectomy was associated with adverse psychological and social consequences. Thirty-six percent of the women reported diminished or greatly diminished satisfaction with their body appearance after prophylactic mastectomy. Some women reported adverse effects in level of emotional stability (9%), level of stress (14%), self-esteem (18%), sexual relationships (23%), and feelings of femininity (25%). Three women reported adverse consequences on every psychological and social variable.

**Figure 1.** Frequency of Psychological and Social Outcomes of Prophylactic Mastectomy




Each outcome was scored on a 5-point scale as greatly increased, increased, no change, diminished, or greatly diminished.

**Figure 2.** Satisfaction With Prophylactic Mastectomy (N=562)




Data are missing for 10 study participants.

### Satisfaction With Prophylactic Mastectomy

Seventy percent of the women were either satisfied or very satisfied with their prophylactic mastectomy. In contrast, 19% were dissatisfied or very dissatisfied (FIGURE 2). When asked whether they would choose to have prophylactic mastectomy again, 67% indicated

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they definitely or probably would (FIGURE 3). Eighteen percent indicated that they probably or definitely would not choose prophylactic mastectomy again. There was a moderately strong correlation between satisfaction with prophylactic mastectomy and decision to have the procedure again ($r$=0.63; $P$<.001). Level of satisfaction was not influenced by age, length of time since procedure, or whether a woman was in the moderate-risk or high-risk group. In addition, level of satisfaction was not influenced by whether the woman had a simple or subcutaneous mastectomy after controlling for whether a woman had reconstruction (TABLE 3).

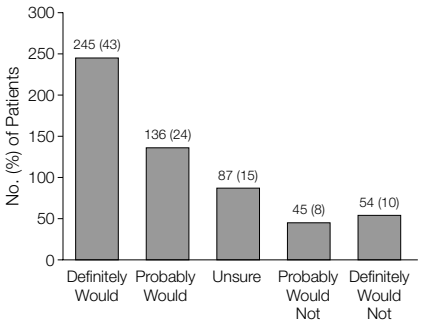
### Variables Associated Most Strongly With Satisfaction With Prophylactic Mastectomy

In terms of simple correlation, satisfaction with body appearance ($r$=0.49; $P$<.001), self-esteem ($r$=0.38; $P$<.001), limited impact on sexual relationships ($r$=0.32; $P$<.001), and lower level of stress in life ($r$=0.27; $P$<.001) were related most strongly to increased satisfaction with prophylactic mastectomy.

The variables identified by multiple regression to be associated with satisfaction were increased satisfaction with body appearance, lower level of stress in life, fewer problems with implants, no reconstructive surgery, no change or improved sexual relationships, family history of breast cancer as a reason cited for prophylactic mastectomy, and decreased emotional concern about developing breast cancer (TABLE 4). These 7 variables explained 36% of the variability in satisfaction with prophylactic mastectomy; 34% was explained by the first 4 variables listed. Collinearity diagnostics revealed that correlation among variables was not problematic for the regression models.

In addition to evaluating all reasons a woman listed for prophylactic mastectomy, we also considered only the first reason cited. With this approach, all variables identified as significant in the multiple regression model remained so, with 1 exception. Family history of breast cancer was replaced by physician's advice in the model and was associated with a lower level of satisfaction. This combination of variables explained 38% of the variability in women's satisfaction with prophylactic mastectomy, with 36% of the variability explained by 4 variables: satisfaction with appearance, lower levels of stress after prophylactic mastectomy, fewer problems with implants, and physician's advice as the primary reason for prophylactic mastectomy.

**Figure 3.** Choice to Have Prophylactic Mastectomy Again (N=567)




Data are missing for 5 study participants.

### Open-ended Comments About Satisfaction

In response to an open-ended question asking reasons for their level of satisfaction, women who were satisfied or very satisfied with prophylactic mastectomy most frequently cited peace of mind, good health since procedure or no problems with procedure, satisfaction with body image and sequelae, and risk reduction or enhanced detection of cancer. Women who were dissatisfied or very dissatisfied with prophylactic mastectomy most frequently reported adverse symptoms or complications including implant concerns, adverse body image and sequelae, and insufficient information or support.

### Level of Contentment

We assessed the level of contentment across the following variables: satisfaction with prophylactic mastectomy, choice to have prophylactic mastectomy again, and the 7 psychological and social function measures. No one responded negatively to all items. One woman responded negatively to all items except reduced emotional concern about developing breast cancer. Ten percent of the women reported dissatisfaction or negative consequences for more than half of the 9 aforementioned variables; 57% were dissatisfied with at least 1 of the 9 variables.

**Table 3.** Comparison of Satisfaction With Prophylactic Mastectomy: Simple vs Subcutaneous (N = 550)*

| Type of Prophylactic Mastectomy | No. of Patients | Very Satisfied or Satisfied, % | Neutral, % | Dissatisfied or Very Dissatisfied, % |
|---|---|---|---|---|
| Subcutaneous, with reconstruction | 504 | 69 | 11 | 20 |
| Simple, no reconstruction | 19 | 100 | 0 | 0 |
| Simple, with reconstruction | 30 | 63 | 20 | 17 |

*Subcutaneous, no reconstruction not reported as only 9 individuals fit this category; satisfaction data are missing on 10 study participants.

## COMMENT

A decision to proceed with prophylactic mastectomy is a major, irreversible step. There has been intense speculation about possible psychosocial sequelae of this procedure. With this study we provide long-term follow-up of a defined cohort of women with a family history of breast cancer who had bilateral prophylactic mastectomy. At a mean of 14.5 years after surgery, the majority of women reported satisfaction, a diminished level of emotional concern about developing breast cancer, and that they would likely choose the procedure again. Additionally, the majority of women reported favorable effects or no change in self-esteem, satisfaction with body appearance, feelings of femininity, sexual relationships, level of stress in life, and overall emotional stability. However, there were some women who were negative in their responses. The top 3 rea-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sons cited for having prophylactic mastectomy were family history, physician's advice, and nodular breasts.

The variable most strongly associated with satisfaction after prophylactic mastectomy was satisfaction with body appearance. Other variables strongly associated with satisfaction in our study were lower level of stress in life, fewer problems with implants, and no reconstruction after prophylactic mastectomy. Physician's advice as the primary reason for choosing prophylactic mastectomy was associated with dissatisfaction.

Why were women who did not have breast reconstructive surgery more satisfied? It is possible that these women place less emphasis on their breasts as part of their self-definition. Related literature supports that women with breast cancer who choose breast conservation over mastectomy are more concerned with their body image, self-esteem, and adjustment to the loss of their breast.[12,13] In our study, women who chose not to have reconstructive surgery compared with women who chose to have immediate reconstructive surgery reported fewer adverse outcomes with feelings of femininity (17% and 28%, respectively) and body appearance (26% and 37%, respectively). Moreover, women who did not have reconstruction would not have been exposed to concerns about implants and other problems with reconstructive surgery.

For some women, prophylactic mastectomy was associated with dissatisfaction and/or adverse psychological and social consequences. The level of dissatisfaction in our study is higher than that found by other researchers.[6,7] Borgen et al[7] reported that only 5% of a group of 370 women who had prophylactic mastectomy had significant regrets about the procedure 15 years later. But their sample, consisting of volunteers who answered an advertisement published in many magazines, may have selected women with more favorable experiences. Stefanek et al[6] reported that all of the 14 women in their study were satisfied with prophylactic mastectomy 6 to 30 months after the procedure. However, they were less satisfied with their reconstructive surgery. Because 95% of our cohort had reconstructive surgery, our patients' responses reflect their experiences with both prophylactic mastectomy and reconstructive surgery.

Are responses to satisfaction questions colored by women wanting to provide socially desirable responses? We do not think so. Women in this study commented freely on areas of dissatisfaction when answering the open-ended questions. Moreover, 57% of the women reported unfavorable scores on at least 1 of the satisfaction and psychosocial items.

We compared satisfaction and psychological and social function among women at high risk for breast cancer who, prior to their prophylactic mastectomy, did and those who did not have a sister diagnosed as having breast cancer. We found no statistically significant differences between women at high risk for breast cancer, who prior to their prophylactic mastectomy, did and those who did not have a sister diagnosed as having breast cancer. However, there was a trend toward higher satisfaction in women at high risk for breast cancer who, prior to their prophylactic procedure, had a sister diagnosed as having breast cancer compared with women who, prior to their prophylactic mastectomy, did not have a sister diagnosed as having breast cancer (79% and 64%, respectively, were satisfied; 9% and 23%, respectively, were dissatisfied; $P = .07$). Seventy-two percent of the women who, prior to their prophylactic procedure, had a sister diagnosed as having breast cancer would probably or definitely choose to have prophylactic mastectomy again compared with 67% of the women who, prior to prophylactic mastectomy, did not have a sister diagnosed as having breast cancer. Eleven percent and 19%, respectively, would probably not or definitely not choose the procedure again. There were no significant differences between groups on the 7 psychological and social variables.

Despite fitting a comprehensive model, factors identified as strongly associated with satisfaction accounted for only 36% to 38% of the variability in levels of satisfaction. Clearly, satisfaction is multifaceted and highly personal. Ideally, we would like to be able to identify those women preoperatively who are most likely to be satisfied or dissatisfied with prophylactic mastectomy.

**Table 4.** Relationships Identified as Those Most Strongly Associated With Increased Satisfaction

| Variable | *r* | β | *P* |
|---|---|---|---|
| Increased satisfaction with appearance | 0.49 | .56 | <.001 |
| Lower level of stress in life | 0.27 | .18 | <.001 |
| Fewer problems with implants | 0.16 | .13 | .003 |
| No reconstruction | 0.13 | .16 | .001 |
| No change or improved sexual relationships | 0.32 | .14 | .004 |
| Family history of cancer as a reason for electing procedure | 0.08 | .12 | .02 |
| Decreased emotional concern about developing breast cancer | 0.22 | .09 | .05 |

When analyzing reasons for choosing prophylactic mastectomy, our retrospective approach has limitations. The chief concern is that recall of reasons may be colored by subsequent experiences. For example, we found some association between dissatisfaction and listing physician's advice as the primary reason for prophylactic mastectomy. This can be interpreted in at least 2 ways. One, some physicians pressured women into this decision, contributing to long-term dissatisfaction. Or, given the retrospective nature of our decision-making assessment, those women who are now dissatisfied attribute their original decision to physician advice. Clearly, the role of the health care professional is to provide data about all options in a balanced manner. The primary motivation for the procedure must derive from the patient herself.

It has been suggested that the decision to have prophylactic mastectomy is driven by irrational fear.[14,15] Of the 572 study participants, 3% listed psychological or emotional factors as the primary reason for prophylactic mastectomy; 22% listed it as 1 of their top 3

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reasons. Clearly, concern about breast cancer is what motivates a woman to pursue any possible prevention or early detection strategy. What level of concern prompts a woman to pursue a given strategy is an individualized decision. The majority of women provided more than 2 reasons for prophylactic mastectomy, suggesting that their decision followed the weighing of multiple factors.

Seven of the entire bilateral mastectomy cohort of 639 women developed cancer after bilateral prophylactic mastectomy. Six of them were alive at the time of survey administration. None of the women voiced dissatisfaction and 5 of the 6 said they would "definitely" or "probably would" choose prophylactic mastectomy again. One response was neutral for satisfaction. Likewise, 1 response was neutral for choice to have the procedure again. Comments related to rationale for satisfaction included that it was the best decision at the time, that they were comfortable with their body image, it provided peace of mind, and that it provided risk reduction or enhanced detection of cancer. One woman was dissatisfied with the cosmetic results and 1 woman reported that the procedure gave her a false sense of security.

During the study period, subcutaneous mastectomy was performed more commonly than it is at present. Advances in breast and nipple reconstruction, as well as the more complete removal of breast tissue with total mastectomy, make total mastectomy the preferred prophylactic procedure for the majority of women at high risk of breast cancer.

In conclusion, these data provide additional information to women contemplating prophylactic mastectomy. While the majority of women are satisfied with prophylactic mastectomy and would choose it again, there are some women who are neutral in their response or dissatisfied with this procedure. Our role as health care professionals is to provide a woman with a family history of breast cancer the best available information and encourage her to take time to consider all the options now available. Positive outcomes following prophylactic mastectomy include a significant reduction in breast cancer risk,[1] decreased emotional concern about developing breast cancer, and generally favorable psychological and social outcomes. These must be weighed against the irreversibility of the decision, potential problems with implants and reconstructive surgery, and adverse psychological and social outcomes in some women.

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