

# BILATERAL PROPHYLACTIC MASTECTOMY: EFFICACY, SATISFACTION, AND PSYCHOSOCIAL FUNCTION

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**ABSTRACT:** *A minority of women at increased risk for breast cancer chooses to undergo prophylactic mastectomy (preventive removal of breast tissue). This article discusses their reasons for choosing to have prophylactic mastectomy and their long-term satisfaction with this procedure. Effects on body appearance, feelings of femininity, sexual relationships, and emotional concern about developing breast cancer are reviewed. Data from the Mayo Clinic and elsewhere show the efficacy of prophylactic mastectomy in lowering the risk of breast cancer in high-risk women. A recent study by the Mayo Clinic shows that prophylactic mastectomy provides favorable satisfaction, psychological, and social outcomes for most, but not all, women. This study provides high-risk women and healthcare providers with objective information to use in decision-making about prophylactic mastectomy.*

## Introduction

Breast cancer is prevalent in our society. In 2003 212,600 women are projected to develop breast cancer.<sup>1</sup> The risk of developing breast cancer increases with age, from 1-in-2044 at age 20 to 1-in-24 by age 70. The lifetime chance for developing invasive breast cancer is 1-in-8.<sup>2</sup> The death rate from breast cancer was stable from the 1930s until 1990, when it began to decrease as a result of earlier diagnosis, most likely from the increased use of mammography. Currently, 86 percent of women with breast cancer survive at least five years after their diagnosis.<sup>2</sup>

Only 5% to 10% of all breast cancers are due to a family history or a genetic predisposition. A person carrying a breast cancer gene alteration has a greater risk of developing breast cancer than the general population. People with a BRCA1 or BRCA2 alteration have a 56% to 87% lifetime chance of developing breast cancer.<sup>3-5</sup> While we know there are other BRCA alterations than BRCA1 and BRCA2, these are the only ones that we can currently test.

Families with a breast cancer gene alteration are usually diagnosed with breast cancer at a very young age, and breast cancer affects several relatives. However, not every family member in families with a known genetic alteration is affected by that alteration. Children only have a 50% chance of inheriting the alteration from their parent affected by the alteration.

People with a very strong family history have very difficult clinical decisions to make. Their options are screening by mammography, breast self-examination and annual healthcare professional examination; tamoxifen; and prophylactic mastectomy. Screening will not decrease their risk for breast cancer, but will assist in diagnosis at a very early stage. Tamoxifen reduces the risk of breast cancer by approximately 50%; however, it has side effects.<sup>6</sup> Prophylactic mastectomy requires surgical intervention and is irreversible.

There are three types of prophylactic mastectomy: subcutaneous, total, and skin sparing. The majority of people in our study had

subcutaneous mastectomies in which the entire breast was removed except for the nipple/ areola area and approximately 5% of the breast tissue behind the nipple. The nipple/areola was kept intact to improve cosmetic appearance. Since the advent of better breast reconstruction, subcutaneous mastectomy is not as common.

A total or simple mastectomy, where the entire breast tissue is removed but lymph nodes are left intact, is probably the most common procedure today. Most women have breast reconstruction with the nipple/areola area reconstructed or tattooed. More recently, skin-sparing techniques are used in which all of the breast skin, except for the nipple and areola, is spared. The breast is reconstructed through the incision made to excise the nipple/areola. The cosmetic results are remarkable, however, this procedure is not widely available.

We know that breast tissue is not confined to any given spot on the chest wall, so even after removal of most of the breast tissue, breast cells remain. Through studies

with radiographic contrast and dye, we know that breast tissue extends into the axilla, sternum, and epigastric area tissue.<sup>7-8</sup> Biopsies after subcutaneous mastectomy have identified residual breast tissue.<sup>9</sup> Patients have developed breast cancer after having a prophylactic mastectomy.

### Opinion and Efficacy Research

Generally, 16% to 20% of women at high-risk for breast cancer rate prophylactic mastectomy as a favorable option, and 9% to 17% of women who express interest in prophylactic mastectomy proceed with the procedure.<sup>10-12</sup> Stefanek et al.<sup>13</sup> studied 58 women who were not interested in prophylactic mastectomy, 92 women who were interested but decided against surgery, and 14 women who proceeded with prophylactic mastectomy. They found no difference between the three groups in age, family history of breast cancer, or belief in the ability to detect breast cancer early or prevent it. There were some significant differences: women who were not interested in prophylactic mastectomy rated the 10-year estimate of breast cancer risk lower than those who were interested in the procedure, women with a history of biopsy were more likely to be interested in prophylactic mastectomy, and women who proceeded with the surgery were more worried about breast cancer than women who did not proceed with surgery.

A study by Hartmann et al.<sup>14</sup> of the Mayo Clinic looked at the efficacy of bilateral prophylactic mastectomy in women with a family history of breast cancer. This was a retrospective cohort study of 639 women: 425 of moderate risk (family risk) and 214 of high risk (family history indicated that a genetic alteration was likely in that family). For the moderate-risk group, a Gail model predicted that 37.4 women would develop breast cancer and 10.4 would die. In the

prophylactic mastectomy group, four women developed breast cancer and none died from the disease. This was an 89% reduction in the occurrence of breast cancer and a 100% reduction in breast cancer deaths (Table 1).

**TABLE 1**  
**Efficacy of Prophylactic Mastectomy**  
**(Hartmann et al., New Engl J Med.)**

#### Moderate-Risk Group

89% reduction in breast cancer occurrences  
100% reduction in deaths due to breast cancer

#### High-Risk Group

90% reduction in breast cancer occurrences  
81% to 94% reduction in deaths due to breast cancer

In the high-risk group, sisters (403) who did not have prophylactic mastectomy were compared to sisters who did have the procedure (214). Sisters experienced 30 to 52.9 breast cancers and 10.5 to 30.6 deaths (variation dependent on whether all breast cancers and deaths were counted or only those that occurred after the prophylactic procedure). Women who had prophylactic mastectomy had 3 breast cancers and 2 deaths, resulting in a 90% reduction in breast cancer occurrences and an 81% to 94% reduction in breast cancer deaths.

Subsequently, data on the 26 BRCA1 and BRCA2 carriers in this cohort were examined.<sup>15</sup> We had a median follow-up of 13.4 years. The prediction models told us that three to nine breast cancers would occur among these carriers. There were only three women with breast cancer in the entire cohort of 214 high-risk women; two were screened for BRCA1 and BRCA2 and were negative (we were unable to get a blood specimen from the third woman).

We have also begun to look at the efficacy of contralateral prophylactic mastectomy in 745 women who had breast cancer in one breast and also had the other breast removed.<sup>16</sup> Eight women developed a contralateral breast cancer, six of whom were pre-menopausal. Using the Anderson model, 106 pre-menopausal women were predicted to develop breast cancer. Thus, a 96.4% risk reduction was realized in pre-menopausal women with contralateral prophylactic mastectomy. Two of the women who developed breast cancers after contralateral prophylactic mastectomy were post-menopausal (over the age of 50). Fifty of these women were predicted to develop breast cancer based on the Anderson model. Thus, contralateral prophylactic mastectomy in this post-menopausal group resulted in a 96% risk reduction.

### Psychological and Social Research

In terms of psychological and social data, four main questions drove the research (Table 2).

**TABLE 2**

#### The Main Questions in Psychosocial Research

- What reasons do women describe for having had a prophylactic mastectomy?
- How does prophylactic mastectomy affect women's long-term psychological and social function?
- How satisfied are women with prophylactic mastectomy?
- What factors are associated with satisfaction/dissatisfaction with prophylactic mastectomy?

These questions are important because prophylactic mastectomy is controversial, with strong proponents and strong opponents. In

addition to efficacy data, a balanced understanding of benefits and adverse effects associated with this procedure was needed.

Very few studies were published prior to our study. Borgen et al.<sup>17</sup> conducted a study with 370 women who had a bilateral prophylactic mastectomy between 1945 and 1996. The majority of these women (75%) had reconstruction, and 69% had one first degree relative with breast cancer. The median follow-up time was 14.6 years and the mean age of the women was 45 years. Ninety-five percent of the women were satisfied with their prophylactic mastectomy. Of the 5% who expressed regrets, 10 women rated their regret as major, 7 as minor, and 4 did not rate their regret. Three women developed breast cancer; only one expressed regret about the prophylactic mastectomy. Those with unfavorable outcomes said the physician initiated the discussion about the prophylactic mastectomy. Borgen's study was limited, however, because subjects were solicited by magazine advertisements, so it is likely that they had more favorable responses.

Stefanek et al.<sup>13</sup> conducted a study of 14 women who had a bilateral prophylactic mastectomy between 1988 and 1992. Their mean age was 37. Eleven women had breast reconstruction. The study was conducted an average of 5.7 months after they had the surgery. One hundred percent of the women were satisfied with their decision and three women were dissatisfied with the reconstruction. The limitation of this study was its small sample size.

Our study was a series of 639 consecutive women who had bilateral prophylactic mastectomy between 1960 and 1993 at the Mayo Clinic; all had a family history of breast cancer and 609 were living. We surveyed the 609 women through a mail questionnaire with telephone follow-up. The participation rate was 94%.

Follow-up after their prophylactic mastectomy was 14.5 years. The mean age of the women was 42 years at prophylactic mastectomy and 57 years when they completed the survey. Eighty-one percent were married. Sixty-five percent were in the moderate risk group and 35% were in the high-risk group.

Ninety-one percent of the women had subcutaneous prophylactic mastectomy and 9% had simple prophylactic mastectomy. Ninety-five percent had reconstruction with implants.

We asked the women for their reason for having prophylactic mastectomy. Family history was most frequently the number one choice, followed by doctor's advice and nodular breasts. Ninety-eight percent of the women reported one or more reasons and 82% reported two or more reasons.

We asked how their prophylactic mastectomy affected them in terms of their self-esteem, satisfaction with their body appearance, feelings of femininity, sexual relationship(s), emotional concern about developing breast cancer, level of stress in life, and overall emotional stability. We had them rate these variables on a scale from greatly increased to greatly diminished. We saw a similar pattern of response for self-esteem, femininity, and sexual relationships; 75% to 82% of the women reported no change or favorable effects on these variables (Table 3).

Body appearance was negatively affected to a greater degree: 48% of the women reported no change, 36% reported adverse effects, and 16% reported favorable change (likely due to reconstruction). Women experienced similar effects on stress in life and emotional stability: 86% to 91% reported no change or favorable effects. Seventy-four percent of women had diminished emotional concern about developing breast cancer, 20% had no change, and 6% had increased concern.

**TABLE 3**  
**Mayo Clinic Psychosocial Research**

**Most frequent reasons for prophylactic mastectomy:**

Family history  
Doctor's advice  
Nodular breasts

**Impact on self-esteem, femininity, and sexual relationships:**

No change or favorable effects on these variables: 75% to 82%

**Body appearance:**

No change: 48%  
Adverse effects: 36%  
Favorable change (likely due to reconstruction): 16%

**Stress in life and emotional stability:**

No change or favorable effects: 86% to 91%

**Emotional concern about developing breast cancer:**

Diminished: 74%  
No change: 20%  
Increased concern: 6%

**Satisfaction with prophylactic mastectomy:**

Satisfied: 70%  
Neither satisfied or dissatisfied: 11%  
Dissatisfied: 19%

We asked women how satisfied they were with their prophylactic mastectomy. Seventy percent of the women were satisfied, 11% were neither satisfied nor dissatisfied, and 19% were dissatisfied.

We asked women if they would choose to have prophylactic mastectomy again, knowing what they know now. Sixty-seven percent said they would, 15% were unsure, and 18% said they would not.

We were concerned about the women who were dissatisfied with their prophylactic mastectomy and wanted to learn more, so we performed a multiple regression to see if we could identify variables that were strongly identified with dissatisfaction/satisfaction.

We were looking at variables that were strongly correlated. Women who were more satisfied with their prophylactic mastectomy were more satisfied with their body appearance, had lower levels of stress after the surgery, had few problems with implants, and did not have reconstruction (this was a small group of women who likely felt a strong sense of body image without breasts). Variables that were strongly associated with satisfaction but played a less significant role in explaining individual satisfaction were: no change in or improved sexual relationships, family history of breast cancer as the reason for prophylactic mastectomy, and a decreased emotional concern about breast cancer.

### Summary

A high-risk woman's decision to have prophylactic mastectomy is a complex process motivated by a combination of reasons. The most frequently cited reasons for prophylactic mastectomy were family history, nodular breasts, and doctor's advice. The majority of women reported no change in psychological and social function, diminished emotional concern about developing breast cancer, satisfaction with prophylactic mastectomy, and said they would choose the procedure again. The variables explaining differences in satisfaction with prophylactic mastectomy were satisfaction with body appearance, lower level of stress in life, fewer problems with implants after prophylactic mastectomy, and no reconstruction.

### Conclusions

Our previous data substantiated the efficacy of prophylactic mastectomy in lowering the risk of breast cancer in high-risk women. Current data provide high-risk women and healthcare providers with objective information to use in decision-making. They show that prophylactic mastectomy provides favorable satisfaction, psychological, and social outcomes for most, but not all, women.

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