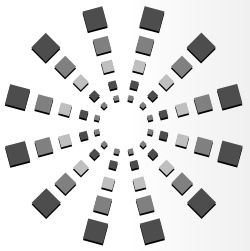

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What Women Wish They Knew Before Prophylactic Mastectomy

KEY WORDS
Breast cancer
Informational needs
Prophylactic mastectomy

Although prophylactic mastectomy significantly reduces the incidence and recurrence of breast cancer, little is known about women's information needs before the procedure. We surveyed 967 women, from 6 healthcare systems, with bilateral or contralateral prophylactic mastectomy performed between 1979 and 1999. There were 2 open-ended questions: ''What one thing do you wish you had known before your prophylactic mastectomy'' and ''Is there anything else you would like to share with us?'' Three researchers categorized responses, and informational needs were ascertained. Seventy-one percent (684 women) responded, of which 81% answered one or both open-ended questions. There were 386 comments (made by 293 women) that related to information needs; 79% of women had bilateral prophylactic mastectomy and 58% had contralateral prophylactic mastectomy. Most concerns (69%) were related to reconstruction: the longevity; look and feel of implants, pain, numbness, scarring, and reconstruction options. Many women wished they had seen photographs to better prepare them for the final result. Our findings suggest that information needs of many women undergoing prophylactic mastectomy, particularly those selecting bilateral prophylactic mastectomy, have not been sufficiently addressed. Clinicians and health educators should be aware of patient needs and must counsel women accordingly.

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This study was funded by the National Cancer Institute (U19 CA79689-030, Increasing Effectiveness of Cancer Control Interventions, Edward H. Wagner, MD, PI and RO1-CA090323, Patient Oriented Outcomes of Prophylactic Mastectomy, Ann M. Geiger, PhD, PI).

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Accepted for publication January 30, 2007.

Although prophylactic mastectomy is a highly invasive procedure, women select this surgery to lower their breast cancer risk. Some may be at high risk for breast cancer due to family history of the disease, others may have obtained screening for BRCA 1 and 2 mutations and been found to be positive.[1–6] For women with a history of unilateral breast cancer facing the possibility of subsequent cancer in the contralateral breast, prophylactic mastectomy has been shown to reduce breast cancer risk.[7–10] In addition, studies of bilateral prophylactic mastectomy have found reductions in subsequent breast cancer incidence of 90% and greater.[2,3] It may also provide gains in life expectancy.[4,8,11] Thus, although the surgery is invasive and irreversible, the risk reduction it affords is often appealing.

Although there is a growing literature on information needs among cancer patients and where they can obtain information,[12–19] there are limited data on the specific information women would like to know when considering prophylactic mastectomy. Researchers have examined satisfaction after both bilateral and contralateral prophylactic mastectomy[20,21] as well as regret related to contralateral prophylactic mastectomy.[11,22,23] One report stated that women who obtained bilateral prophylactic mastectomy wanted more information, but few specifics were offered.[22] Studies claim women benefit from knowledge about the procedure and what to expect following their surgery, often related to cosmetic results,[20,24] but no one has directly asked women what they wish they had known. We used a large, community-based population of women undergoing bilateral or contralateral prophylactic mastectomy, who were initially studied to assess the efficacy of prophylactic mastectomy[1,7] and then were surveyed to examine psychosocial outcomes and quality of life.[25,26] In the survey, we included open-ended questions to ask women specifically what they wish they had known prior to selecting prophylactic mastectomy. This article reports on the information needs women expressed.

■ Methods

Setting

This study was conducted within the Cancer Research Network, a National Cancer Institute–funded collaborative network of 11 healthcare delivery systems committed to the study of cancer prevention, detection, and treatment effectiveness.[27] Six health systems participated: Group Health, Washington; Harvard Pilgrim, Massachusetts; HealthPartners, Minnesota; and Kaiser Permanente in Oregon, Northern California, and Southern California. Approval from the institutional review boards at all sites was obtained.

Subjects

Subjects included all women from each of the 6 systems, who were age 18 to 80 years and who had undergone either bilateral or contralateral prophylactic mastectomy between 1979 and 1999. Those who underwent a bilateral prophylactic mastectomy did so because they were at increased risk for breast cancer due to a family history of the disease. Those who underwent a contralateral prophylactic mastectomy did so after being diagnosed with unilateral breast cancer. Women were identified from automated enrollment, hospitalization, ambulatory care, and cancer registry data. Using chart review, we confirmed that all the mastectomies were done for prophylactic reasons. Further details on this cohort have been published elsewhere.[7,25] Medical charts, automated health plan data, and state mortality records were used to exclude deceased women from the study of psychosocial outcomes. At 5 sites, primary care physicians were contacted and could decline approval for patient participation in the outcomes study. Following the exclusion of subjects due to death, physician refusal, or invalid address, 967 women were identified for the survey: 195 with bilateral prophylactic mastectomy and 772 women with contralateral prophylactic mastectomy.

Mailed Survey

Women were surveyed by mail to examine psychosocial outcomes of prophylactic mastectomy. The first mailing of the self-administered survey was followed 3 weeks later by a second mailing and a telephone reminder 1 month after to women who did not respond to the mailings.[1,7,25,28] The survey was 7 pages long and contained questions about demographics, current quality of life, satisfaction with prophylactic mastectomy decision, breast cancer risk-related worry, body image, sexual satisfaction, and overall health perception. In addition, we included 2 open-ended questions, "What one thing do you wish you had known before your prophylactic mastectomy?" and "Is there anything else you would like to share with us?"

Qualitative Data Analysis

Three researchers (S. R., A. A., L. N.) independently reviewed the responses from the 2 open-ended questions. First, we compiled a list of key words based on the women's comments, and then we developed corresponding domains. Some domains followed the categories of the survey (satisfaction with the decision, body image, sexuality), whereas others emerged from subject responses (implants, reconstruction, social support). Women sometimes made multiple comments over several domains, resulting in multiple comment codes per woman. However, repeated sentiments were coded only once per individual. Discrepancies in coding were discussed until consensus was reached. Within each domain, comments were further examined to identify those that related to information. The coding scheme identified comments expressing both satisfaction and dissatisfaction with the information received.

χ^2 tests were conducted using SAS 8.0 to assess the association of informational needs with contralateral or bilateral prophylactic mastectomy status.

■ Results

Overall, 71% (n = 684) of eligible women responded to the mailed survey. Of those who responded to the survey, 81% (n = 554) responded to one or both of the open-ended questions. Of the total 1,067 comments relating to the prophylactic mastectomy experience, 386 (36%) comments were made by 293 women related to information needs. Women who provided open-ended responses were similar to those who received the survey in terms of demographics, family history of breast cancer, and receipt of reconstruction (Table 1).

Women's Informational Needs

Overall, 102 of the 293 women (35%) explicitly stated that they were satisfied with the information they received before the procedure (Table 2). However, nearly two-thirds wished they had more information, with women undergoing bilateral prophylactic mastectomy more likely than women undergoing contralateral prophylactic mastectomy to indicate informational needs (79% vs 58%, P = .004). Most comments on insufficient information related to reconstruction and implants (181 of 262; 69%), specifically issues of the longevity, look and feel of implants, and complications such as pain, scarring, and numbness. For those who had undergone bilateral prophylactic mastectomy, these accounted for 81% of comments about inadequate information, compared with 64% of comments by women with contralateral prophylactic mastectomy (P = .008).

Reconstruction, Implants

The specific concerns most frequently expressed regarding reconstruction and implants are presented in Table 3. Representative quotes are included. All topics listed had at least 10 comments and comprised 118 of the 181 comments in this domain. The most common topic mentioned (24 women) was the need for better information about "the high rate of implant failure." Although some of the concerns were about the potential of rupture, "I worry that they will break," most comments referred to actual ruptures or replacements. Women mentioned their experiences with implant ruptures

Table 1 • Characteristics of Women With Bilateral or Contralateral Prophylactic Mastectomy by Survey Response

	Addressed Information in Open-Ended Questions (n = 293)		Responded to Survey (n = 684)	
Characteristic at Survey	n	%	n	%
Prophylactic mastectomy type				
Bilateral	72	24.6	117	17.1
Contralateral	221	75.4	567	82.9
Year of prophylactic mastectomy				
1979–1984	20	6.8	46	6.7
1985–1989	43	14.7	100	14.6
1990–1994	95	32.4	232	33.9
1995–1999	135	46.1	306	44.7
Age, years				
<45	24	8.2	46	6.7
45–54	82	28.0	174	25.4
55–64	121	41.3	258	37.7
≥65	66	22.5	206	30.1
Race/ethnicity				
White	254	86.7	592	86.5
Nonwhite	39	13.3	92	13.5
Education*				
Not a college graduate	170	58.8	408	60.4
College graduate	119	41.2	267	39.6
Family history of breast cancer				
Any first degree	116	39.6	234	34.2
Any second or third degree	39	13.3	91	13.3
None	75	25.6	202	29.5
Adopted or unknown	63	21.5	157	23.0
Had reconstruction				
Yes	199	67.9	401	58.6
No	94	32.1	283	41.4

*Data missing for 4 women addressing information and 9 women responding to survey.

Table 2 • Numbers of Women With Informational Comments and Areas of Inadequate Information

	Women With CPM	%	Women With BPM	%	Total Women	*P* Value CPM vs BPM
Women satisfied with information received	87	42	15	21	102	
Women stating informational needs	134	58	57	79	191	.004*
Totals	221		72		293	
Comments on Areas of Inadequate Information						
Comments on CPM vs BPM	**CPM**	**%**	**BPM**	**%**	**Total**	**P**
Reconstruction and implants (longevity, complications, nipples)	118	64	63	81	181	.008*
Timing of reconstruction	6	3	1	1	7	.364
Possibility of negative emotions following prophylactic mastectomy	15	8	7	9	22	.826
Visual results of prophylactic mastectomy and/or reconstruction (desired photos)	11	6	1	1	12	.096
Support groups prior to surgery	7	4	1	1	8	.278
Prophylactic mastectomy less painful/traumatic than expected	4	2	3	4	7	.443
Miscellaneous comments on informational needs	23	13	2	3	25	.012*
Total comments	184		78		262	

*Statistically significant.
CPM indicates contralateral prophylactic mastectomy; BPM, bilateral prophylactic mastectomy.
Women may have commented on various areas of inadequate information but within each area are only counted once.

and number of replacements. One woman stated "I was told the implants would last until the end of my life" and was disappointed when this was not the case. Many expressed disappointment and frustration with "leakage" and "breaking." Some women also offered suggestions for improvement. One wrote, "I think they should make implants with no latex." Another suggested implants be designed as a "honeycomb insert," which would be "firmer and less likely to rupture."

There were several comments about pain and discomfort (n = 22), the unnatural or asymmetric result of implants (n = 15), scarring (n = 15), and numbness (n = 10). Some women wished they had more information on reconstruction options (n = 12) and healing time (10), or the specific risks of silicone implants (n = 10).

Some comments also mentioned the look and effects on nipples as a result of implants. Women indicated they were led to believe that nipples would look real, but described their results as "very fake," "not real" and "phony." Some also commented on the loss of sensation. Some wished they would have had more information on the overall dramatic impact their body; "the permanence and appearance of reconstruction is shocking." Many wished to have had an opportunity to view photographs before the procedure to gain a "realistic view about end results." There were comments on when reconstruction could be done. Most were disappointed that they had to wait, expressing the preference to have had all surgery at one time. Other comments related to reconstruction and implants mentioned the pressure of implants, the possible risk of infection, how to treat an infection, the effect breast surgery has on one's balance, the impact that reconstruction has on abdominal muscles, and possible postsurgery exercises, including when it would be safe to start them.

Negative Emotions and Need for Counseling Following Prophylactic Mastectomy

Twenty-two women wished they had known more about the potential for negative emotions following the prophylactic mastectomy. There were no differences by bilateral or contralateral status. Some women mentioned feeling depressed following the procedure, stating they no longer felt "whole" or "feminine" or "sexually attractive." This was true for women both with and without committed relationships. The permanent change in their bodies was difficult and these women felt unprepared. One wrote, "Women having prophylactic mastectomy need to have emotional follow-up counseling and this should not be optional." The importance of counseling also was noted by 4 women who did not experience negative emotions. They indicated that they felt "very well prepared," but mentioned that it would be beneficial for husbands or partners to get information presurgery. One woman wrote, "While I was very well prepared, he was not." Another commented, "husbands should be helped to really understand this as well as their wives." In addition to individual or couple counseling, some women wish they had known about support groups.

Other Informational Needs

Although several women commented on their negative emotions, there were 7 who commented that they wished they had known that prophylactic mastectomy was *less* traumatic and less painful than anticipated. Women undergoing contralateral mastectomy were more likely to offer comments we classified as miscellaneous (P = .012). These comments, mentioned by 1 or 2 women each, pertained to risk of recurrence, benefits of lumpectomy versus mastectomy, details specific to a woman's individual circumstances, more presurgery information on the prophylactic mastectomy procedure, the need for mammography, resources for purchasing bras, and suggestions for healthy eating and vitamin intake.

■ Discussion and Conclusion

Discussion

We found that 36% of the comments to open-ended questions related to information needs prior to prophylactic mastectomy and nearly two-thirds of the women commenting expressed a desire to have had more information on a variety of topics, most notably, reconstruction and prostheses. The other third were satisfied with the information received. Women with bilateral prophylactic mastectomy reported more informational needs than those with contralateral prophylactic mastectomy and were significantly more interested in getting increased information about reconstruction

Table 3 • Representative Quotes About What Women Wish They Had Known About Reconstruction and Implants Prior to Prophylactic Mastectomy (total number of women commenting are in parentheses)

Topic
Implant rupture/replacement/removal (n = 24)
• I asked about implant leaking, breaking, etc. I was told no. After the fact it seems the implant may need to be replaced in the future.
• I was told the implants would last until the end of my life.
• The high rate of implant failure. I have had 3 replacements in 12 years.
Pain/discomfort of implants/expanders (n = 22)
• Implants are much harder than I thought they would be.
• How much pain I would continue to have in my chest even after 4½ years.
• Expanders made it difficult to sleep on my stomach, although it did not alter my decision.
• How tough it would be, more pain than I expected.
Unnatural look of implants (n = 15)
• I feel the plastic surgeon was not honest about the look and feel of the reconstruction. He made it sound like the breasts would look very much like before, not true. I would have liked photographs.
• I was under the impression that reconstruction would have better results.
• I wish I had seen better photos of reconstruction on others after a year or so. If I had seen how I could look, I would not have been so traumatized by the prospect of mastectomy.
• Better information on placement options.
Scarring (the size and extent) (n = 15)
• The extent of scarring.
• How different my 2 scar sites look. I'm a crooked-looking scar map.
• More information on scar treatment.
Reconstruction options/transflap procedure (n = 12)
• More information on choices of implants.
• I was not informed that they would remove all my abdominal muscles and replace same with a large piece of mesh.
• More about reconstruction using tissue from my body rather than implants.
• The amount of procedures, surgeries required for total reconstruction.
Numbness (n = 10)
• How numb everything would be—4 years later its still numb including my whole abdomen from the tram flap.
• I wish I knew I would lose feeling in my chest and it would last so long.
• I have absolutely no feeling in my breasts.
Information on healing (n = 10)
• That it would take about 2 years after the surgery for me to feel comfortable with my body.
• That this would affect my balance.
• How long it would take to get feeling back in my nipples.
• Reconstruction and healing would take so long.
The risks of silicone (n = 10)
• I could have made a better choice of implants, the silicone destroyed considerable tissue. I now have saline implants.
• There are so many problems for women that received silicone implants. I worry about mine causing medical problems.
• How toxic silicone implants were and are. The physician's ignorance and close-mindedness of implant toxicity on the body and the harm it caused physically was inexcusable.

and implants. This is possibly due to the fact that these women underwent contralateral prophylactic mastectomy as part of their breast cancer treatment, and thus, had been given a great deal of information prior to their procedure. Also, those women who had faced cancer may be more focused on issues of survival than of appearance. Despite the expressed need for more information, a large majority of both groups of women were satisfied with their decision to obtain the procedure. These results complement previously reported findings on satisfaction with the decision made to undergo prophylactic mastectomy (87% of women with contralateral prophylactic mastectomy and 84% of women with bilateral prophylactic mastectomy) and subsequent quality of life.[25,26]

Like others, we found that women with both contralateral and bilateral prophylactic mastectomy wished to have a realistic expectation of physical results of prophylactic mastectomy and of reconstruction.[20,22,24] This was true throughout the time span covered regardless of approach to reconstruction. Some women also made comments about the need for comprehensive counseling to increase awareness of negative emotions, real and potential, surrounding the procedure. Josephson et al[29] reported a need for increased psychosocial support for women obtaining bilateral prophylactic mastectomy and concluded that a multidisciplinary team including a psychologist was optimal. Few women in our study expressed this need but felt that information sessions for friends and family members could be beneficial to address both factual and support issues.

The study had limitations. Women were surveyed 3 to 22 years after the prophylactic mastectomy, with a median of 9 years. Had we asked for information needs closer to the time of surgery, the responses may have been different. On the other hand, the time gap may have allowed the women to report on enduring issues following prophylactic mastectomy. Women in our study received either total or subcutaneous prophylactic mastectomies, the approach to which has not changed appreciably over time (T. Morris, personal communication, September 20, 2006). Implant material has varied over time, by local practice patterns and due to legislation of acceptable products, however, recovery time, follow-up, and overall patient concerns have been fairly consistent. Another potential limitation is that all women in this study were members of integrated healthcare delivery systems and may not be fully representative of all women selecting prophylactic mastectomy. However, these systems are large, geographically diverse, and community based.

There were also several strengths to our study. First, the number of women surveyed was large and, as mentioned, community based. We were also able to collect information from women with both contralateral and bilateral prophylactic mastectomy, something that has not been done in other studies. In addition, with over 80% of respondents offering comments to one or both open-ended questions, it is clear they have suggestions for improving the care provided as women consider and undergo this surgery. This high level of response provided a rich source of data.

Conclusion

The decision to obtain a prophylactic mastectomy is a major and irreversible one. Women, even aware of the decreased cancer risk conferred by the procedure, must consider the associated physical and emotional ramifications that they may face following the surgery. In addition to photographs of women after prophylactic mastectomy and reconstruction, findings from our study suggest that women would benefit from a full understanding of all options available to them and be better prepared about the potential for pain, numbness, scarring, and the physical changes that may occur as the result of the surgery selected.

Practice Implications

In Table 4, we have summarized the content of all comments to provide an overview of information that could be covered

Table 4 • Recommended Patient Information in Preparation for Prophylactic Mastectomy

About the Procedure(s)
What the prophylactic mastectomy procedure will entail
Various surgeries available
Nipple removal
Risk reduction as a result of the procedure
When reconstruction could occur
Options for reconstruction
Implants
Types of implants
Look and feel of implants
Risk of infection and how to treat infection
Expected longevity of implants
Potential complications of prophylactic mastectomy and reconstruction
Pain/discomfort
Numbness
Scarring
Effect on balance
Preparing psychologically
Potential of depression
Potential of relief
Issues related to body image, sexuality, and self-esteem
Recovery time
General healing process
Range of recovery time
Range of recovery time related to complications
Cosmetic results
Expectations of how one will look
Photos of women with prophylactic mastectomy (showing a range of worst, typical, and best outcomes)
Photos of women with reconstruction (showing a range of worst, typical, and best outcomes)
Look and sensation of nipples
Follow-up after prophylactic mastectomy
Types of bras and where to buy them
Support groups
Postsurgery exercises
Future mammography

as providers prepare women for this surgery. Clinicians and health educators should be aware of informational needs and find ways through printed materials, one-on-one meetings, or group support sessions, to advise women accordingly.

ACKNOWLEDGMENTS

The authors would like to thank Dana Rickey for her extensive work on the database, and the project coordinators at each site for their contributions to this study. In addition, we thank all the women who participated in the survey.

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