

The psychosocial impact of bilateral prophylactic mastectomy: prospective study using questionnaires and semistructured interviews

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Abstract

Objectives To investigate the psychosocial impact of bilateral prophylactic mastectomy for women with increased risk of breast cancer and to identify, preoperatively, risk factors for postoperative distress.

Design Prospective study using interviews and questionnaire assessments.

Setting Participants' homes throughout the United Kingdom.

Participants 143 women with increased risk of developing breast cancer who were offered bilateral prophylactic mastectomy and who accepted or declined the surgery; a further 11 were offered surgery but deferred making a decision.

Main outcome measures Psychological and sexual morbidity.

Results Psychological morbidity decreased significantly over time for the 79 women who chose to have surgery (accepters): 58% (41/71) preoperatively *v* 41% (29/71) 6 months postoperatively (difference in percentages 17%, 95% confidence interval 2% to 32%; $P = 0.04$) and 60% (39/65) preoperatively *v* 29% (19/65) 18 months postoperatively (31%, 15% to 47%; $P < 0.001$). Psychological morbidity in the 64 women who declined surgery (decliners) did not decrease significantly: 57% (31/54) at baseline *v* 43% (23/54) at 6 months (14%, 0% to 29%; $P = 0.08$) and 57% (29/52) at baseline *v* 41% (21/52) at 18 months (16%; -2% to 33%; $P = 0.11$). Greater than normal proneness to anxiety was more common in the decliners than in the accepters: 78% (45/58) *v* 56% (41/73) (22%, 6% to 38%; $P = 0.006$). Accepters were more likely than decliners to believe it inevitable that they would develop breast cancer (32% (24/74) *v* 10% (6/58) (difference in percentages 22%, 9% to 35%; $P = 0.003$)), and decliners were more likely to believe that screening could help (92% (55/60) *v* 74% (55/74) (18%, 5% to 31%; $P = 0.007$)). Level of sexual discomfort and degree of sexual pleasure did not change significantly over time in either of the two groups.

Conclusions Bilateral prophylactic mastectomy may provide psychological benefits in women with a high risk of developing breast cancer.

Introduction

Bilateral prophylactic mastectomy may significantly reduce development of breast cancer in women at increased risk,¹ but as it is a radical surgical intervention the psychological costs and benefits are important to establish. Published reports tend to be personal accounts of the decision to undergo surgery or of living with the threat of the disease,^{2,3} or they are case studies describing women's reactions to the impact of the disease on themselves and their family and the difficulties they faced in decision making.^{4,5}

One study reported that women's decisions to have prophylactic mastectomy were based on their biopsy history, subjective perceptions of risk, and degree of worry about cancer.⁶

Postoperative regret about having decided to undergo surgery was reported in a retrospective study even though the proportion was small (6% of 370 participants).⁷ To date, little prospective research has been published in large samples of women about the factors influencing decision making or the psychosocial implications of prophylactic surgery.⁸

Important psychological benefits from surgery may include a reduction in chronic anxiety and worry, in distress associated with false positive mammography results, and in dependence on screening and self examination.⁹ For women who fear developing the disease, the putative psychological benefits of surgery may well outweigh any negative consequences.

We measured—by using interviews and questionnaire assessments—psychological morbidity in women at increased risk of developing breast cancer who were offered bilateral prophylactic mastectomy, regardless of whether they accepted the option.

Method

Participants

Women at increased risk of developing breast cancer were referred to us by clinicians working in 20 participating centres throughout the United Kingdom. All women gave written informed consent to join the study, which had local and regional ethics approval. Interviews and completion of questionnaires were conducted in the participants' homes.

Eligibility criteria were having a family history of breast cancer or having sufficiently high risk factors for bilateral prophylactic mastectomy to be offered. Genetic status was determined by the referring clinicians. Most women reported a risk of carrying the gene of between 1 in 2 and 1 in 4.

Of 168 women eligible to join the study, 154 women were recruited, 79 chose surgery (accepters), 64 declined (decliners), and 11 deferred making a decision while awaiting results of gene testing, completing their family, or seeking further information.

Most women (73% (58/79) of accepters, 83% (52/63) of decliners) were in paid occupations. The age range was similar for both groups (26-57 (median 38) years *v* 22-56 (40) years). Most women had children (81% (64/79) *v* 75% (48/64)).

Interviews

All women had their first interview as soon as possible after they were referred to the study. The accepters were interviewed again at 6 and 18 months postoperatively; the median time from first interview until surgery was 17 weeks, range 2 days to 125 weeks. Women who



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Table 1 Comparisons of percentages of women scoring ≥ 4 (threshold for possible psychological morbidity) on general health questionnaire, based on numbers of women completing questionnaires at all relevant time points

Assessments	Accepters*			Decliners†		
	% (proportion)	Difference (%) (95% CI)	P value	% (proportion)	Difference (%) (95% CI)	P value
Baseline v 6 months	58 (41/71) v 41 (29/71)	17 (2 to 32)	0.04	57 (31/54) v 43 (23/54)	14 (0 to 29)	0.08
Baseline v 18 months	60 (39/65) v 29 (19/65)	31 (15 to 47)	<0.001	57 (29/51) v 41 (21/51)	16 (-2 to 33)	0.11

CI=confidence interval. *Women who had surgery. †Women who declined surgery.

declined or deferred making a decision were interviewed again 18 months after the first interview. The interviews were semistructured, with questions phrased to elicit information on decision making, perceptions of risk, and psychosocial implications of surgery.

Most women made their decision on whether to have surgery at the time of the first interview, regardless of whether they had seen a surgeon or felt they had all the necessary information. A small minority changed their decision at a later date, on receipt of a positive or negative blood test result.

Questionnaires

Six questionnaires were used in the study.

- The “general health questionnaire 30” is a screening tool to determine psychiatric morbidity in clinical or community settings.¹⁰
- The “Spielberger state-trait anxiety inventory” is a clinical tool for evaluating current state of anxiety (state) and proneness to anxiety (trait).^{11,12}
- The “sexual activity questionnaire” is used to assess sexual functioning.¹³⁻¹⁵
- The “ways of coping questionnaire” is a checklist devised to assess coping strategies used to deal with a specific stressful event.¹⁶
- The “risk perception questionnaire” is used to assess knowledge of risk.^{17,18}
- The “body image scale” is used to assess women’s perception of their body image, applicable across disease sites and treatment methods.¹⁹

Analysis

As the distributions of the outcome measures were frequently skewed, non-parametric statistical tests were used. The χ^2 test was used to compare differences in proportions, except where the observations were paired, in which case the McNemar test was used. Paired, continuous observations were compared by using the Wilcoxon test, and independent groups were compared by using the Mann-Whitney U test.

Baseline statistical analysis included all women who completed the assessment at the first interview. In subsequent analyses, only those women who completed assessments at each time point were included.

Results

General health questionnaire

Table 1 shows the results from the general health questionnaire. Psychological morbidity decreased signifi-

cantly over time among the accepters, and the longer the time from surgery, the greater the decrease. Even though there was a trend, the proportion of decliners scoring ≥ 4 did not differ significantly between the first (baseline) and the 6 month assessment. Over 50% of decliners had psychological morbidity at the first assessment, and this did not decrease significantly over an 18 month period. No significant differences existed between the two groups of women at any of the three time points.

Spielberger state-trait anxiety inventory

The women’s scores for anxiety as a trait (tested at baseline) were compared with published normative values for women in this age group; a significantly higher proportion of decliners (45/58) than accepters (41/73) were prone to anxiety, indicated by a normative score > 35.6 (22% risk difference, 95% confidence interval 6% to 38%).

The proportion of accepters with state anxiety above the normative score decreased between the preoperative and the 6 month postoperative assessment and between the preoperative and the 18 month postoperative assessment (table 2). The proportion of decliners scoring above the normative value did not differ significantly between the baseline and the 6 month assessment and the baseline and the 18 month assessment.

Sexual activity questionnaire

Sexual discomfort changed little over time within or between groups, with median scores being very close to the maximum of 6 (indicating no discomfort). Among accepters, the median was 6 at all times. Among decliners the median score did not change significantly over the three time points. No significant differences in sexual pleasure were found between or within groups. Degree of sexual pleasure did not change significantly over time in either of the two groups.

Ways of coping questionnaire

The median score for using problem focused coping was significantly higher among accepters than among decliners (16 v 14, $P = 0.03$); the median score for using detachment as a coping mechanism was significantly higher among decliners than among accepters (7 v 3, $P < 0.001$).

Body image scale

When the body image questionnaire was administered postoperatively to the accepters (most of whom had

Table 2 Comparisons of percentages of women scoring above normative score of 36.2 (indicating high anxiety) on Spielberger state anxiety questionnaire, based on numbers of women completing questionnaires at all relevant time points

Assessments	Accepters			Decliners		
	% (proportion)	Difference (%) (95% CI)	P value	% (proportion)	Difference (%) (95% CI)	P value
Baseline v 6 months	69 (47/68) v 40 (27/68)	29 (15 to 44)	<0.001	54 (26/48) v 54 (26/48)	0 (-13 to 13)	1.00
Baseline v 18 months	71 (45/63) v 41 (26/63)	30 (14 to 46)	0.001	52 (24/46) v 50 (23/46)	2 (-11 to 15)	1.00

The higher the score, the greater the anxiety.

had immediate reconstruction) at the 6 and 18 month interviews, no differences in the median score of 4 (range 0-30, with 0 indicating most positive body image) were detected (median change 0, 95% confidence interval 0 to 1; $P=0.84$). Scores were similar to those published recently of women with breast cancer who had immediate reconstruction.²⁰

Risk perception questionnaire

Although most women in both groups reported perceived risk levels of between 1 in 2 and 1 in 4, the accepters overall tended to report higher lifetime risks of developing breast cancer than the decliners. In particular, accepters were more likely than decliners to believe it inevitable that they would develop the disease. Decliners were more likely than accepters to believe that screening could help (92% (55/60) *v* 74% (55/74); difference in percentages 18% (95% confidence interval 5% to 31%); $P=0.007$).

Investigatory and genetic tests

Accepters were more likely than decliners to have had an investigatory test (fine needle aspiration, biopsy, or lumpectomy) (43% (34/79) *v* 19% (12/64); difference in percentages 24% (10% to 39%); $P=0.002$) or a gene test (29% (23/79) *v* 5% (3/64); difference 24% (13% to 36%); $P<0.001$).

Discussion

Our primary aim was to evaluate the psychosocial impact of bilateral prophylactic mastectomy by comparing psychological morbidity in women who have had the procedure with women who have been offered but declined the procedure. High levels of psychological morbidity and anxiety before surgery reduced significantly over time after surgery. In women who declined surgery and opted for regular surveillance and screening, high levels of psychological morbidity and anxiety were maintained.

Our results are concordant with those from a US study which hypothesised that bilateral prophylactic mastectomy reduced chronic anxiety and worry, while women attending a family history clinic but not participating in any other prevention programme had

increased anxiety.⁹ Conversely, other authors reported that 24 women with a family history who did not attend a family history clinic had significantly higher anxiety scores than 47 women with a family history who were attending a clinic and participating in a chemoprevention trial comparing tamoxifen with placebo.²¹ These authors surmised that participation in a prevention programme, or attendance at a specialist clinic, alleviated anxiety.

In our study the women who declined surgery had significantly higher scores for anxiety as a personality trait than those who had surgery, which may explain why the high levels of anxiety and psychological morbidity among decliners did not decrease over time. The women who declined also tended to use detachment to cope, rather than the problem focused approach used more frequently by those who had surgery. The statements reflecting use of detachment (such as "I try to forget the whole thing") are much more passive than the problem focused statements (such as "I'm making a plan of action and following it"). Although they seemed to be more anxious, the women who declined surgery were less inclined to act on their anxiety.

It is encouraging to note that the women who had surgery (most of whom had had immediate reconstruction) maintained a positive body image and reported few or no changes in sexual activity at each time point, although longer follow up studies are needed.

Further research is also needed to look at the best method of ensuring that risk perception is accurate. A recent study found that genetic counselling produced only a modest shift in the accuracy of perceived lifetime risk.²² We found that 32% of women who had surgery believed it inevitable that they would develop breast cancer. If women are making decisions based on inaccurate perceptions they might regret these decisions later. Although our study found no evidence for this up to 18 months after surgery, future research needs to include a longer follow up. Inaccurate perceptions of lifetime risk, coupled with the greater number of investigatory tests, confirms another report that women choosing surgery had undergone more biopsies and reported higher risk estimates than those who declined.⁶ In another study of women at high genetic risk, entry into a chemoprevention trial was higher in women who believed themselves to be at greater personal risk.²³

Conclusion

Women who chose to have surgery strongly believed that removal of breast tissue would significantly reduce their chances of developing the disease. The fact that such a high percentage of these women believed that they would inevitably develop cancer may explain both their decision to have the prophylactic surgery and their reduction in anxiety and psychological morbidity postoperatively.

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Contributors: LF, with Angela Hall and Kathryn Thirlaway, designed the pilot study. MBH was the primary coordinator of the study, conducting most of the interviews with women and collating and analysing the data. RAH was the statistical adviser for the study from its inception. MBH, LF, and RAH all contributed to final the analysis and writing of the paper. LF is the guarantor for the paper.

What is already known on this topic

Little is known of the psychological and social impact of bilateral prophylactic mastectomy for women with increased risk of developing breast cancer

Women's decisions to undergo the surgery may be based on biopsy history, subjective perceptions of risk, and degree of worry about cancer

What this study adds

Bilateral prophylactic mastectomy reduces psychological morbidity and anxiety and does not have a detrimental impact on women's body image or sexual functioning

Women who choose such surgery have a higher, often inaccurate, perception of their risk of developing breast cancer

Genetic counsellors need to ensure that women's decisions to have surgery are based on accurate perceptions

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"Patient knows best"—detection of common mental disorders in Santiago, Chile: cross sectional study

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Depression and anxiety are common in primary care but about half of patients with these disorders are not identified by primary care physicians.^{1,2} Mental disorder is more likely to be diagnosed in patients who present with or attribute physical symptoms to psychological causes.³⁻⁴ We investigated how patients' ways of understanding their health problems influenced the detection of common mental disorder by primary care physicians in Santiago, Chile.

Methods and results

We studied 815 consecutive patients seen by 11 primary care physicians from five randomly selected clinics in northern Santiago, Chile. Patients with a chronic illness or patients aged over 50 were excluded because these patients are better known by doctors. Most doctors in Chile and in this study have less than four years' experience in primary care.

Before the patient saw the doctor, a lay interviewer asked the patient's reason for consultation and whether it was because of a physical or psychological problem. The interviewer inquired about other potential confounders: physical illness, disability, common somatic symptoms, and whether patients tended to interpret common somatic symptoms by using psychological, physical, or normalising explanations.

A psychiatrist administered the clinical interview schedule—revised, and patients scoring 12 or more were classified as having a common mental disorder.⁵

After the patient had seen the primary care physician, the doctor rated blindly whether the patient had a mental disorder using a five-point scale. Patients with a rating of "mild or greater" severity were considered to have a mental disorder.

The prevalence of mental disorders was 49% (396 of 802; 95% confidence interval 46% to 53%) according to the clinical interview schedule—revised and 35% (276 of 796; 31% to 38%) according to the doctors' ratings. Agreement of doctors' ratings was 48% (186 of 385; 43% to 53%) with the psychiatric assessment ($\kappa=0.27$), so 52% (199 of 385; 47% to 57%) of the cases identified by the clinical interview schedule went undetected. As a whole, 34% (269 of 795; 30% to 37%) of the patients chose a psychological explanation for their reason for consultation but only 69% (185 of 269; 63% to 74%) of them were psychiatric cases according to the psychiatric interviewer.

When analysis was restricted to psychiatric cases, almost half (48%) (186 of 389; 43% to 53%) of these patients attributed their reason for consultation to psychological causes. Among psychiatric cases, doctors identified correctly 34% (70 of 204; 28% to 41%) of those who attributed their reason for consultation to physical causes and 63% (116 of 185; 55% to 70%) of those who attributed their presenting problems to a psychological cause. After adjustment for confounders three variables showed significant independent associations with detection (table): a spontaneous

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