ELSEVIER

European Journal of Cancer 40 (2004) 365–374

European Journal of Cancer

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Preoperative psychological reactions and quality of life among women with an increased risk of breast cancer who are considering a prophylactic mastectomy

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Received 27 May 2003; received in revised form 3 July 2003; accepted 8 August 2003

Abstract

A consecutive sample of 56 women with a familial risk for breast cancer who were considering a prophylactic mastectomy (PM) completed questionnaires preoperatively concerning risk perception, expectations with regard to surgery, anxiety and depressive symptoms (the Hospital Anxiety and Depression Scale (HAD) scale) and quality of life (The Swedish SF-36 Health Survey). 16 had had a previous breast cancer (Group BC) and 40 had not (Group R). They were compared with normative data from an age-matched random sample of the Swedish population and with a reference sample of women with breast cancer. Most women estimated their breast cancer risk accurately. No statistically significant differences were found between Group BC and the normative sample on the HAD scale and SF-36, but Group R reported better physical functioning, emotional role functioning and mental health than the reference sample with breast cancer. Group BC scored closer to them than to the normative sample. Levels of emotional problems and quality of life were comparable to normative values among women considering PM. All women in the present study had previous genetic counselling and our results suggest that their interest in PM was not due to an overestimation of their personal risk.

Keywords: Preoperative psychological reactions; Increased risk; Breast cancer; Prophylactic mastectomy; HAD scale; quality of life; SF-36

1. Introduction

Several screening and preventive strategies are possible for women with a personal and/or family history of breast cancer. Clinical and self-examination of the breasts, mammography, ultrasound, magnetic resonance imaging, hormonal interventions and prophylactic mastectomy (PM) are presently being evaluated [1,2]. Bilateral PM, as a means of reducing the risk of breast cancer among women in hereditary breast cancer families, is controversial [3]. In a retrospective study, it was claimed that PM substantially reduces the risk of manifest breast cancer in all women with an increased risk of developing breast cancer [4]. The incidence of breast cancer in female carriers of mutations in one of the two identified breast cancer genes, *BRCA1* and *BRCA2*, was reduced after PM [5] and it was concluded that PM offers a life expectancy gain for young women with BRCA-associated early-stage breast cancer [1]. However, PM has been considered by some to be too drastic and the associated negative psychosocial effects too large to motivate such extensive surgery in healthy women [6].

The proportion of women with a family history of breast cancer seeking advice regarding PM varies in different populations and is probably influenced by a number of factors. Among these factors are risk perception, incidence and mortality patterns in relatives, availability of surgeons conducting PM, the approach used when informing women about the preventive

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doi:10.1016/j.ejca.2003.08.026

alternatives, as well as cultural differences. In an Austrian study, 21% of female mutation carriers ($n=7$) reported an interest in PM [7]. A similar proportion, 19% ($n=64$) considered PM before disclosure of the results of a mutational screening in an Australian study [8]. In a US study, 35% ($n=11$) of the mutation carriers considered PM after disclosure of their test results [9]. In a Dutch study, as many as 51% ($n=35$) of eligible patients carrying *BRCA1*/*BRCA2* mutations underwent PM within 2 years after disclosure of their test results [5].

It has been shown that women interested in PM have higher levels of breast-related anxiety than those who do not consider PM [8,10]. The willingness to undergo PM was not associated with the objective risk of breast cancer or with the number of relatives with breast cancer [8]. In an interview study of 41 women following genetic counselling, PM was described as providing women with an increased hereditary risk with a means to reduce the risk and fear of cancer [11]. Adverse effects of PM were also described in that study, e.g. compromising social obligations, risk of complications before and after the operation, effects on body image, identity and sexual relationships [11].

In a retrospective Swedish study, 15 women who had undergone PM with immediate breast reconstruction (conducted between 1993 and 1997) were interviewed [12]. The most important issue for these women was the risk reduction. The cosmetic result of the operation exceeded the patient's initial expectations. No woman regretted her decision to have a PM. Recently, a study of 143 British women offered PM because of an increased risk of breast cancer indicated that psychosocial morbidity significantly declined in those 79 women that underwent surgery, in contrast to these 64 women who did not choose surgery [13]. Another British study of 76 women who completed surgery between 1995 and 1999 showed that there was no evidence of mental or body image problems in the first three years following PM, but the most frequently reported changes were in sexual attractiveness. Those who had complications after the surgery were in need of additional psychological help [14]. Apart from the British studies, there is a lack of prospective studies on the decision-making process and the psychological consequences of having a PM [10,15].

The principal aim of our study was to describe the risk perception, expectations from having a PM, emotional reactions before PM, and quality of life before surgery in two consecutive subgroups of women considering PM because of a personal and/or family history of breast cancer. Another aim was to explore differences in the psychosocial distress experienced between these two subgroups, women considering PM with no breast cancer and women with a previous breast cancer diagnosis who subsequently considered PM. Furthermore, our study samples were compared with an age-matched normative sample and with data from a Swedish study of women with breast cancer in order to explore differences between the two groups of women having a familial risk for breast cancer and two corresponding samples without such a familial risk. In addition, expectations from the reconstructive procedure in our study subjects were compared with those in a sample of women with breast cancer who also considered breast reconstruction.

2. Patients and methods

Since 1992, PM has been considered in women at a high risk of developing breast cancer (K. Sandelin, 2003, data not shown). The increasing number of women referred to the Departments of Surgery and Reconstructive Plastic Surgery, Genetics, and Oncology during the latter part of the 1990s necessitated concerted efforts from all the professionals involved in the decision-making process. A collaborative group, consisting of geneticists, oncologists, a breast surgeon, a plastic surgeon, nurses and a psychologist, was established at the Karolinska University Hospital in 1996. Routine procedures for women considering PM were implemented in 1997.

2.1. Study sample

For women belonging to families with breast or breast/ovarian cancer, oncogenetic counselling has been available at the Karolinska Hospital since 1980. The risk of breast cancer in healthy individuals is based on the information from an extended pedigree. Some women belong to families where an autosomal dominant gene is suspected. Others have an increased risk of disease based on epidemiological studies (Claus tables) [16]. When the two breast cancer susceptibility genes *BRCA1* and *BRCA2* were identified in 1995, families fulfilling the criteria for genetic screening were offered screening for these two genes.

In the past, women with a modest or highly increased risk opting for preventive surgery were initially offered PM, but from 1999, only women with an estimated risk, 40 based on family history or genetic testing were offered PM.

During the study period of 1997–2001, women with a personal and/or family history of breast cancer, who were considering PM, were included. The study group included, in addition to women with no breast cancer (Group R), also women with a previous breast cancer (Group BC). Women in Group R were either referred from general practitioners (GPs), gynaecologists, or other physicians for genetic counselling. Women in Group BC had previously been operated upon for

breast cancer and were under consideration for an extended surgical intervention. For most women, the operation included PM, except in those cases where unilateral PM was already performed because of a previous breast cancer. A total of 63 women discussed the possibility of PM during the study period.

2.2. Procedure

Since 1997, all women with a family history of breast cancer who opt for PM, meet a representative of each of the professionals within the multi-disciplinary collaborative group before making a decision about whether to have a PM. All women underwent genetic counselling and pre-symptomatic testing at the Department of Clinical Genetics at the Karolinska Hospital. The risk for breast cancer in unaffected women was counselled according to the risk of disease in *BRCA1* and *BRCA2*-carriers, or in families without known mutations according to risk estimates using the Claus model [16]. Risk estimates of 60–80% were only used in healthy *BRCA1* or *BRCA 2* gene carriers from families with multiple cases. At the start of the study, no specified criteria for PM based on risk were set, but from 1999, only women with an estimated risk, 40 based on family history or genetic testing were offered PM.

The surgical team consisted of one breast surgeon and one reconstructive plastic surgeon. All of the women were discussed within a multidisciplinary collaborative group, where the expectations and demands of each woman were highlighted and documented. The recommendation from the group was documented and, when indicated, a tentative schedule for PM was set. The woman made the decision as whether to have a PM. However, it was recommended to some women that they wait because the genetic investigation was not completed, or because the time from the first breast cancer diagnosis and treatment was less than two years. When the PM with immediate breast reconstruction was done, the surgical team consisted of one breast surgeon and one reconstructive plastic surgeon.

In the present study, and according to the programme mentioned above, all women considering PM met with the psychologist at least once before the surgical procedure. This meeting lasted for approximately 60 min and included an interview according to a schedule with themes to be covered. The aim of the meeting was to determine the personal history of the woman with respect to her breast cancer risk, to elucidate how she started to consider PM, and her concerns related to PM. The women were asked about the perceived benefits and adverse effects of PM. They were also given the opportunity to express their emotions and considerations related to the risk and to the decision to undergo a PM.

At the beginning of the interview, the women were informed about the aim of the present study. They were informed that the questionnaire responses were not included in the discussion with the multi-disciplinary collaborative group, and that the identification of the questionnaires was through use of a code marked on the questionnaire. A list, linking the codes and the women's names was kept separately, and the code was broken after the woman had decided about PM. After the interview, the women received a questionnaire and were asked to complete it at home and return it in an enclosed prepaid envelope as soon as possible. All of the women consented to this procedure and the questionnaires were returned before surgery. Approval of the study was received from the Local Ethics Committee at the Karolinska University Hospital (May 1997 No:97:137).

2.3. Questionnaires

2.3.1. Perceived risk for breast cancer

Perceived risk for breast cancer was assessed by a modified version of a questionnaire developed in a study of the impact of genetic counselling on risk perception in women with a family history of breast cancer [17]. The perception of the life-time risk for breast cancer was evaluated by each woman, as well as the lifetime risk for breast cancer among women in the general population, both items scored in categories from "100% risk;" to "Very unlikely". Issues like the following were explored for each woman: Had the woman spoken to other family members about her breast cancer risk? Had she felt an increased risk for other cancers? Did she think that breast cancer screening programmes would help her?

2.3.2. Expectations following the reconstruction

An instrument for the assessment of expectations following the breast reconstruction was developed in the women with breast cancer before delayed breast reconstruction (SVEA) study, a prospective study of delayed breast reconstruction after mastectomy for breast cancer [18]. The questionnaire consists of six items measuring expectations of "Life change", "Femininity", "Intimate situations", "Physical activities", "Social activities", and "Ability to work", scored from 1 ("Negatively") to 7 ("Positively"). The questionnaire was also used to assess how these expectations were fulfilled after the operation. Data showed differences in the expectations and also that they were fulfilled to a great extent. The questionnaire was also used in a prospective study of women undergoing breast reduction, showing similar results [19]. Thus, the questionnaire has shown sensitivity in various areas, but no formal validation or reliability testing has been performed.

2.3.3. The Hospital Anxiety and Depression (HAD) scale

The HAD-scale, developed for the assessment of anxiety and depressive symptoms in patients with

somatic diseases, consists of 14 items, 7 measuring anxiety and 7 depressive symptoms, each item scored in 4 response categories (scored 0–3) [20]. The maximum value for each subscale is 21. Categorisation of ''within normal range'' (0-7), ''possible clinical cases'' (8–10) and ''clinical cases'' (=11+) was suggested by the original authors and therefore used in the present paper [20]. The HAD-scale has been shown to be a reliable and valid instrument for the assessment of anxiety and depressive symptoms in previous studies [21]. Normative data from a sample of the Swedish general population have been published in Refs. [22,23].

2.3.4. The Swedish SF-36 Health Survey (SF-36)

The SF-36 was used to measure health-related quality of life [24]. Thirty-six items measured 8 health-related quality of life domains: physical functioning (10 items), role limitations as a result of physical (4 items) and emotional problems (3 items), pain (2 items), general health perception (5 items), social functioning (2 items), vitality (4 items) emotional well-being (5 items), and a single item about change in health. The Swedish version has shown good psychometric properties [25], and normative data for Swedish women were available [26]. The normative study was used for comparison in two Swedish studies of breast reconstruction after mastectomy [27,28].

2.4. Reference samples

The normative study using the SF-36 was conducted from 1991 to 1992 and consisted of 7 population studies, comprising a sample of 8930 Swedish inhabitants (51.4% females) representing 68% of the target population [26]. The mean age was 42.7 years (range 15–93 years). In the present study, normative values using SF-36 for the Swedish population were age-standardised for women 35–54 years of age.

In a randomised study of three different methods for late breast reconstruction, a total of 73 women who were operated upon for breast cancer, completed a questionnaire concerning their expectations on the operation and SF-36 before undergoing a breast reconstruction (the SVEA study) [18,27]. The median time from the primary operation was 1.6 years (range 2 months to 11.8 years). In the present study, the values for SF-36, collected before randomisation, were presented as reference values for women with breast cancer. The patients in the SVEA study can be considered similar to Group BC in this study with respect to having a diagnosis of breast cancer, but they were not characterised by a family history of breast cancer. In the present study, a modified version of the SVEA study questionnaire for assessing the woman's expectations with regard to the operation was used. Thus, values in the SVEA study regarding expectations before breast reconstruction are presented for comparison.

2.5. Statistics

Descriptive data for women in Groups R and BC are given. Differences in SF-36 between the groups were analysed by the Student's unpaired *t*-test with Bonferroni corrections ($P=0.05$) for multiple comparisons.

Differences between Group R and Group BC, in proportion of women reporting positive expectations on PM, i.e. scoring 5–7 on the 7-graded scale, were analysed by Chi^2 tests. The figures from the normative sample used for comparison in the present study have been age-standardised [26]. Mean values and standard deviations (SD) for women in age groups 35–44 years and 45–54 years have been combined.

3. Results

Out of 63 women, evaluated for potential PM between 1997 and 2001, 7 were excluded for the following reasons: the PM would not occur within 2 years ($n=4$), declined participation in the interview study ($n=1$), low risk of breast cancer ($n=1$) and psychiatric illness ($n=1$).

Fifty-six women were therefore included in the study and responded to the questionnaires. Forty women (71%) considered a PM due to a hereditary increased risk for breast cancer (Group R), whereas 16 had a previous diagnosis of breast cancer, as well as a hereditary risk (Group BC). The mean age at the interview was 44 years (range 25–68 years) in the entire sample, 43 years in Group R (range 30–68 years), and 45 years (range 25–55 years) in Group BC. Among the 26 women who had undergone genetic testing, 23 were found to carry a *BRCA1* mutation, 15 in Group R. Three women in Group R carried a *BRCA2* mutation.

So far, 51 of the 56 women included have undergone a PM (June-2003). Five women have not been operated upon (1 with breast cancer in addition to hereditary risk). Four of them decided not to go through the procedure, whereas 1 woman postponed her PM while trying to get pregnant.

The lifetime risk for developing breast cancer was estimated for 36 women in Group R. Five of them (14%) were estimated to have a life-time risk >60%, 15 (42%) to have a 50–60% risk, 11 (31%) to have a 20%–40% risk and 5 of them (14%) were estimated to have a less than 20% risk of developing breast cancer.

3.1. Estimated risk for developing breast cancer

The women in Group R were asked to indicate how they estimated their own risk of developing breast cancer (Table 1). These figures were compared with estimates from the Department of Clinical Genetics. Nine women (25%) overestimated their risk >20%, whereas

Table 1
Women with no breast cancer (Group R): estimated own risk and their risk estimated by proessionals

	Estimated risk by professionals after genetic counselling,% ($n=36$)			
Own estimated risk (%)	80	60	40	20
80–100	2	7	2	0
50	3	2	8	0
25–33	0	3	1	2
⩽20	0	3	0	3
Total	5	15	11	5

10 women (28%) underestimated their risk >20%. Twelve women estimated their risk for breast cancer as =33%. Corresponding estimates from the Department of Clinical Genetics revealed an objective risk of =20% for 5 women in the study.

The women were also asked to estimate the risk of breast cancer for a woman in the general population without a family history of breast cancer. The women in the study sample perceived correctly their own risk as being higher than that for a woman in the general population (data not shown).

3.2. Expectations with regard to the consequences of PM

In general, the women in Group BC, with a previous breast cancer, appeared to have more positive expectations from the operation than those with no breast cancer considering a PM (Group R). Most women expected very few changes, except for "life change", where the majority expected a positive outcome (Table 2).

The proportion of women reporting positive expectations from the operation (i.e. scoring 5–7 on the 7- graded scale) seemed to be higher for most items among the women in Group BC than for those in Group R (Fig. 1). Compared with Group R, a higher proportion of the women in Group BC held positive expectations of their ability to perform physical activities ($Chi^2=7.10$; degrees of freedom (df) = 1; $P<0.01$) and social activities ($Chi^2=4.98$; df = 1; $P<0.05$). No statistically significant differences were found for the other three items.

In the present study, a lower proportion of women appeared to have high expectations when compared with the women in the SVEA study [18].

3.3. Anxiety and depressive symptoms (HAD-scale)

On the HAD anxiety subscale, the mean score for the women in Group R was 5.4 (SD = 3.9) and 6.1 (SD = 5.0) for those in Group BC. The corresponding figures for the HAD depression subscale were 2.3 (SD = 2.6) for Group R and 3.1 (SD = 4.3) for Group BC. No statistically significant differences in the mean values were seen between the groups, although the figures seemed to be higher for women in Group BC than for those in Group R.

Table 2
Women with no breast cancer (Group R, $n=40$) and women with a previous breast cancer (Group BC, $n=16$): Responses to questions regarding expectations with regard to the consequences of PM

	Response categories		
Question	Negative (1–3) *n* (%)	No change (4) *n* (%)	Positive (5–7) *n* (%)
Life change			
Group R	3 (8)	14 (35)	23 (58)
Group BC	3 (19)	1 (6)	12 (75)
Femininity			
Group R	11 (28)	20 (50)	9 (23)
Group BC	4 (25)	5 (31)	7 (44)
Intimate situations			
Group R	17 (43)	16 (40)	7 (18)
Group BC	5 (31)	5 (31)	6 (38)
Physical activities			
Group R	8 (20)	24 (60)	8 (20)
Group BC	1 (6)	6 (38)	9 (56)
Social activities			
Group R	3 (8)	27 (68)	10 (25)
Group BC	0	7 (44)	9 (56)
Ability to work			
Group R	5 (13)	23 (58)	12 (30)
Group BC	1 (6)	6 (38)	0 (56)

The proportion of the women in the three categories "within normal range", "possible clinical case" and "clinical case" are presented in Table 3. Thirty percent reported anxiety and 7% depression that was not within the "normal range".

3.4. Quality of life SF-36

The study results were compared with the normative sample, consisting of 1725 Swedish women, aged 35–54 years, as previously described in Ref. [26]. In addition,

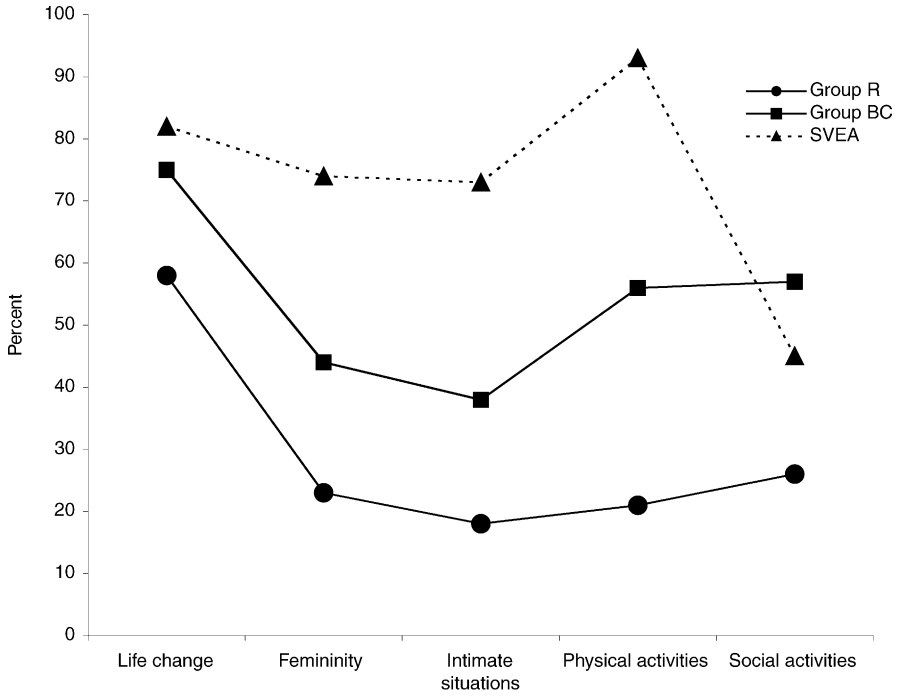

Fig. 1. Percentage of women in the two study groups and in the women with breast cancer before delayed breast reconstruction (SVEA) study responding in categories 5 to 7 (''Positive'') concerning expectations with regard to the operation.

Table 3
Proportion of women in the three categories ''within normal range'' (0–7), ''possible clinical case'' (8–10) and ''clinical case'' (11+) for the HAD anxiety and depression subscales, respectively

Scores	Anxiety			Depression		
	Group R *n* (%)	Group BC *n* (%)	Total *n* (%)	Group R *n* (%)	Group BC *n* (%)	Total *n* (%)
0–7	28 (70)	11 (69)	39 (70)	38 (95)	12 (86)	50 (93)
8–10	7 (18)	1 (6)	8 (14)	1 (3)	1 (7)	2 (4)
11+	5 (13)	4 (25)	9 (16)	1 (3)	1 (7)	2 (4)

HAD, The Hospital Anxiety and Depression Scale.

73 women included in the SVEA study served as a comparison group [18]. A box plot of the data for the eight SF-36 scales for the women in Groups R and BC is presented in Fig. 2. The mean values and SDs for our study samples, for the SVEA sample and the normative sample are shown in Table 4. No statistically significant differences were found between Group R and the normative sample. When Group R was compared with the SVEA sample, statistically significantly higher mean values were found concerning physical functioning ($P < 0.002$) after Bonferroni correction for multiple comparisons. It should be kept in mind that only 16 women were included in Group BC, and therefore any statistical comparisons were likely to be suspect. No other statistically significant differences were found between the groups studied. Fig. 2 shows that Group R had the highest mean scores on all variables, except for social functioning.

4. Discussion

In the present study, a consecutive sample of women considering PM responded to questionnaires concerning risk perception, expectations with regard to the result of the operation, emotional reactions and quality of life. The women studied were divided into two groups, one with a risk for breast cancer due to a family history, and one that, in addition to the familial risk, also had experienced a diagnosis of breast cancer. Both groups were compared with reference values, showing that women without a personal experience of breast cancer resembled the normative sample for most variables, whereas the women having a breast cancer diagnosis had values closer to the ones found in a previous study of women with breast cancer [18,25]. Although our sample groups were small, the results indicated that having a hereditary risk for breast cancer does not lead

to higher levels of anxiety and depressive symptoms, or to a decreased quality of life compared with the levels found among women in the general population. However, those who, in addition to the hereditary risk, also have had a diagnosis of breast cancer, appear to score higher on anxiety and depressive symptoms and lower on some of the quality of life variables. Thus, our results suggest that having a previous breast cancer affects the well-being of a women more than a hereditary risk of breast cancer.

Risk reduction is one of the primary reasons for having a PM [10]. An adequate risk perception is therefore

Table 4
SF-36 scored means and standard deviations (SD) in the study populations and reference values for the general population[a] and for patients with breast cancer.[b] Physical functioning was statistically significantly higher in Group R compared with the SVEA sample, while the other variables failed to reach significance

	Group R ($n=40$) Mean (SD)	Group BC ($n=16$) Mean (SD)	Normative valuea ($n=1725$) Mean (SD)	SVEAb ($n=72$) Mean (SD)
Physical functioning (PF)[c]	92.8 (15.2)	85.0 (21.4)	88.8 (18.1)	80.4 (18.8)
Physical role (RP)	86.2 (28.8)	67.9 (43.2)	85.3 (30.0)	82.9 (30.0)
Bodily pain (BP)	80.3 (25.4)	76.0 (21.1)	72.6 (26.4)	80.7 (23.9)
General health (GH)	79.8 (16.4)	74.6 (23.1)	76.4 (22.7)	76.1 (19.4)
Vitality (VT)	67.6 (24.4)	66.8 (23.2)	67.0 (23.8)	64.5 (20.2)
Social functioning (SF)	88.5 (20.6)	90.2 (18.5)	87.1 (21.7)	83.3 (22.2)
Emotional role (RE)	92.1 (18.1)	88.1 (40.0)	85.9 (28.8)	77.1 (34.3)
Mental health (MH)	81.3 (16.4)	75.4 (25.6)	79.8 (19.5)	73.9 (20.0)

SF-36, The Swedish SF-36 Health Survey.
[a] Values for women, age group 35–54 years, in the normative sample [Sullivan, 1994 #26].
[b] Values before breast reconstruction from women after mastectomy for breast cancer [Brandberg, 2000 #3].
[c] Statistically significant difference between Group R and SVEA ($P=<0.002$) after Bonferroni correction.

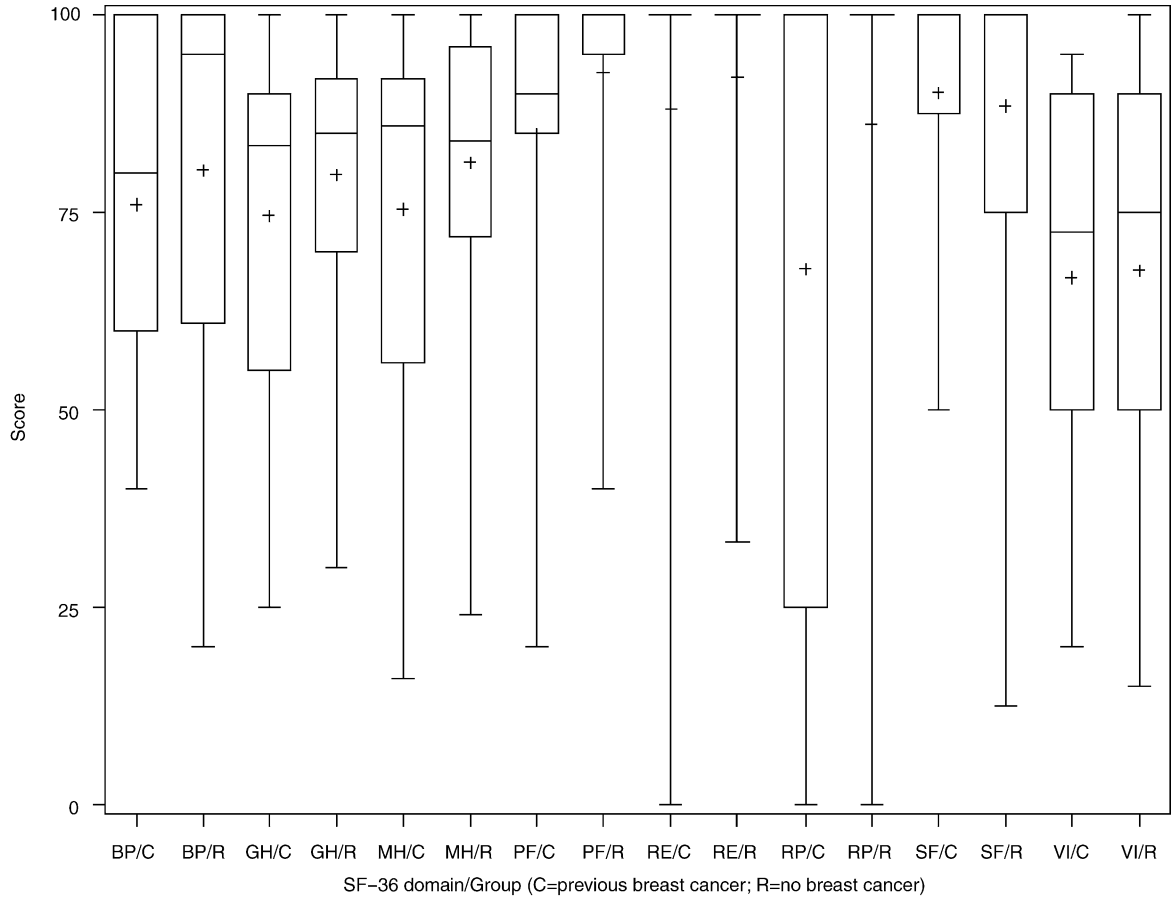

Fig. 2. Data on the eight SF-36 subscales for Group BC (C) and Group R (R) showing mean, median, range. The box includes 50% of the respondents. See Table 4 for definitions of subscales. SF-36, The Swedish SF-36 Health Survey.

important before deciding whether to undergo a PM. The response alternatives, given in the questionnaire assessing subjective risk, did not compare directly to the model for estimation of risk that is used in the counselling process. Overall, the women seemed to have a relatively accurate perception of their risk of breast cancer. Approximately 66% indicated a subjective risk within 20% from the estimation made after genetic counselling by a professional genetic counsellor. In addition, none of the women with a low risk, as estimated by the professionals, indicated a high risk, and none of those with a high risk, as estimated by the professionals, responded that they had a low risk. The risk estimates are not comparable, but indicate that most women makes accurate risk estimates. Other studies of subjective risk perception among women who had undergone genetic counselling report deviations in agreement between objective and subjective assessments of risk, but also that genetic counselling considerably improved the subjective assessment [17,29–31]. After genetic counselling, the reported figures of agreement in two of the studies varied between 31% [30] and 33% [17]. In a study using a questionnaire similar to ours, overestimation of one's risk was associated with a willingness to undergo a PM [8]. In addition, in a study of women at increased risk for breast cancer due to a family history, those who underwent a PM were compared with women who were not interested in having a PM [10]. Patients who underwent a PM indicated a subjective higher risk before surgery than the objective risk estimates, and also a higher risk than those who were not interested in a PM. All the women in the present study had had previous genetic counselling, and for most women, there was no reason to believe that their interest in having a PM was due to an overestimation of their personal risk.

The questionnaire used for assessing expectations from the surgery was developed for a study on breast reconstruction after mastectomy for cancer [18]. Most women in both groups held positive expectations of "life change". Unfortunately, "life change" was not defined. Therefore, this item probably holds different meanings for the women involved. Many women explained that, in addition to not having to worry about the regular surveillance including mammography, they expected that the reduction of their breast cancer risk would change their lives considerably in a positive direction.

The women in Group BC appeared to have more positive expectations of their PM than the women whose entire reason for the operation was to reduce the risk of breast cancer (Fig. 1). One explanation was that the women in Group BC, with a previous breast cancer, were more familiar with the ablative surgery and they also felt a stronger need to further reduce their risk. In addition, some of the women in Group BC had already undergone unilateral mastectomy, and their PM included breast reconstruction. Thus, they were likely to expect cosmetic gains as a result of the forthcoming operation.

Psychosocial morbidity seems to vary between studies of women with an increased risk for breast cancer. Increased psychosocial morbidity has been reported among women with a hereditary risk for breast cancer [32,33]. However, in other studies, levels of psychosocial distress comparable to the general population have been found [29, 34]. The women in Group R, without breast cancer, but having a family history of the disease, reported levels of anxiety and depressive symptoms comparable to the Swedish general population [22,23], but 30% scored over the cut-off point for possible clinical cases on the anxiety subscale. The corresponding figure was 7% for the depression subscale. These figures indicate that anxiety is relatively common, but it might be that the depressed women with a family history of breast cancer do not take the initiative to undergo a PM. Twenty-five percent in Group BC ($n=4$) revealed clinical levels of anxiety. However, considering our small sample, it is difficult to draw conclusions from the prevalence of anxiety in this group. Cancer-related distress has been found to be increased among women with a hereditary risk for breast cancer [30,34]. We have not assessed explicitly the breast-cancer-related distress. Taking the request for PM into account, the women in our study perceived a need to reduce the risk of breast cancer, and, worryingly, probably influenced their lives in such a way that it was reflected in the instruments assessing anxiety, depressive symptoms or quality of life. However, it would have been valuable if specific cancer-related distress had been assessed.

We found no differences in quality of life between the normative sample and Group R [26]. The women in Group BC, with breast cancer, showed reactions similar to the patients in the SVEA sample [18]. Therefore, family history did not seem to affect their psychosocial well-being. A statistically significant difference in any of the quality of life variables is not equivalent to a clinically significant difference. On-going studies now try to estimate the clinical relevance of differences or changes in quality of life scores in some of the quality of life instruments frequently used. However, several methodological problems are involved in this process. It was suggested that a difference of 5–10% on a 100% scale is clinically significant [35]. Thus, in our study, the 15 point difference on the 100-point emotional role subscale, between the patients with a hereditary risk and the breast cancer patients in the SVEA study [18] is probably of clinical significance.

We acknowledge that there is a multiplicity problem in performing a large number of statistical tests. The main aim of this paper was to provide a thorough description of this group of patients, rather than testing

a few *a priori* hypotheses. Thus, the *P* values presented here should be interpreted with caution and considered as an indication of differences that may merit further investigations. However, considering our small sample, the data suggest that there may be other differences between the groups that are not detected in this study.

We decided to separate the questionnaire data from the clinical discussions, in order to maintain confidentiality and also to increase the possibility of obtaining reliable responses concerning the items about sexuality and expectations from the PM (for example), which might be considered too intimate to respond to openly. We think it unlikely that the questionnaires would reveal problems that were not apparent in the interviews, since they both covered the same issues.

The present study reports from a setting where women with a family history of breast cancer are counselled concerning PM. The woman herself makes the decision to go through with a PM, but before that she sees a number of specialists for discussion. This concept is presented to all the women concerned, and, to date, no woman has rejected this approach. Physicians initiating discussions about having a PM were shown to predict regrets that occurred after the operation [36,37]. Our routine includes at least one consultation with a designated specialist in genetics, oncology, breast surgery, plastic surgery and psychology before the PM is performed. For most women, this process takes about a year, giving women the possibility to reflect upon their options: i.e. having a PM or regular clinical follow-ups. Our follow-up programme includes regular visits to the Department of Plastic and Reconstructive Surgery, where a specialist nurse is employed to look after these women. The programme also includes one consultation with a psychologist and regular yearly follow-ups at the oncology out-patient clinics. Most women have expressed their satisfaction with this procedure. However, we have not evaluated the procedure itself, and, possibly, the preoperative reactions among women considering a PM would be different in another setting. All the women in the present study participated in a 2-year follow-up study after the PM.

In conclusion, a consecutive sample of women with a family history of breast cancer referred for a discussion of whether to undergo PM from 1997 to 2001 reported a relatively adequate risk perception. Women with no breast cancer held lower expectations with regard to the results of the operation than those having a previous breast cancer. In both groups, the levels of anxiety, depressive symptoms and quality of life were similar to those found among women of the same age in the Swedish population. Women with a previous breast cancer showed reactions that were similar to those found among patients with breast cancer.

Acknowledgements

This work was supported by grants from The King Gustaf V Jubilee Fund, Stockholm, The Swedish Cancer Society and The Swedish Association for Cancer and Traffic Victims.

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