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# The course of distress in women at increased risk of breast and ovarian cancer due to an (identified) genetic susceptibility who opt for prophylactic mastectomy and/or salpingo-oophorectomy ☆

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ABSTRACT

The levels and course of psychological distress before and after prophylactic mastectomy (PM) and/or prophylactic salpingo-oophorectomy (PSO) were studied in a group of 78 women. General distress was measured through the hospital anxiety and depression scale (HADS), cancer-related distress using the impact of events scale (IES). Measurement moments were baseline (2–4 weeks prior to prophylactic surgery), and 6 and 12 months post-surgery. After PM, anxiety and cancer-related distress were significantly reduced, whereas no significant changes in distress scores were observed after PSO. At one year after prophylactic surgery, a substantial amount of women remained at clinically relevant increased levels of cancer-related distress and anxiety.

We conclude that most women can undergo PM and/or PSO without developing major emotional distress. More research is needed to further define the characteristics of the women who continue to have clinically relevant increased scores after surgery, in order to offer them additional counselling.



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## 1. Introduction

Women with an identified BRCA1/2 mutation have a cumulative lifetime risk (*i.e.* up to the age of 70 years) for breast cancer of 39–85%, and for ovarian cancer of 10–63%. Furthermore, after a history of breast cancer, the life-time risk of contralateral breast cancer is 35–64%.[1] Female 50% risk carriers from families with an autosomal dominant transmission pattern of breast and/or ovarian cancer without an identifiable BRCA1/2 mutation also have an increased risk, whereby the risk of developing breast cancer is estimated by means of genetic-epidemiological tables.[2]

Unaffected mutation carriers and 50% risk carriers can either opt for regular surveillance of the breasts and ovaries, or for prophylactic mastectomy (PM) and/or prophylactic salpingo-oophorectomy (PSO). Mutation carriers who have been treated for breast cancer may opt for (bi- or contralateral) PM and/or PSO in selected cases. Both types of prophylactic surgery are associated with substantial risk reduction with respect to the development of a primary breast or ovarian cancer,[3–8] while prospective data on the benefit regarding overall survival are not yet available. However, prophylactic mastectomy is associated with the loss of healthy breasts and normal sensation, and is an irreversible procedure.[9] Further, breast reconstruction, either immediate or at a later stage, may require re-operation(s), usually for implant-related issues.[9,10] Research[11,12] pointed out that balanced information is of importance for careful decision making regarding PSO.

Favourable effects of prophylactic surgery on a woman's distress level[13–22] and quality of life[3] in the year following these interventions have been reported.[23] Apparently, the disease-induced fear was relieved after surgery. Most of these observations were obtained from retrospective studies in small samples of women.[15,22,24] To our knowledge, a prospective exploration of the levels and the courses of distress in women undergoing a PM versus a PSO has not been performed yet. Within the framework of a prospective study on the medical and psychosocial effects of prophylactic surgery that started in 1999 at the Family Cancer Clinic of the Erasmus MC in Rotterdam, the levels and courses of general and cancer-related distress were analysed in women undergoing either a PM and/or a PSO. The main goal was to examine whether PM and/or PSO would cause major psychological distress. Our research questions were the following: (1) do women opting for prophylactic surgery experience higher distress levels prior to surgery than women adhering a regular breast cancer surveillance programme, (2) is there a relief of distress after PM and/or PSO, and (3) are the levels and courses of distress different between women opting for PM and, respectively, for PSO? Moreover, we explored the frequency of scores considered to indicate clinically relevant distress.

## 2. Patients

### 2.1. Study population

Between August 1999 and February 2003, 129 high-risk women who decided to undergo PM and/or PSO as risk reducing procedure at the Family Cancer Clinic of the Erasmus MC-Daniel den Hoed Cancer Center were invited to participate in a psychological follow-up study (PREVOM-B study) on the psychological impact of prophylactic surgery. All women came from families with an apparent autosomal dominant transmission pattern, and therefore had an associated elevated risk of breast/ovarian cancer. The majority of these women were BRCA1/2 mutation carriers (hereafter called 'mutation carriers'). For women from hereditary breast-(/ovarian) cancer families without a detectable BRCA1/2-mutation (hereafter called 'risk carriers'), the request for PM/PSO was reviewed at the multidisciplinary patient meeting of the working party on hereditary cancer of our institution. The decision to proceed to prophylactic surgery was made after extensive and repeated information and counselling. Factors taken into account were age, previous history of cancer, risk calculation to develop breast cancer and/or ovarian cancer, and consistency of the patient's request and its underlying arguments.

Only women having prophylactic surgery at the Erasmus MC-Daniel den Hoed Clinic in Rotterdam were eligible for this study. Also, no signs or suspicion of breast/ovarian cancer should be present in unaffected women at pre-surgical examination (physical and imaging examination, plus Ca125 analysis) performed within 3 months prior to surgery. Women with a history of breast/ovarian cancer were to have no signs of recurrent disease or a new primary breast or ovarian cancer after physical and imaging/dissemination examination consisting of mammography, gynaecological ultrasound, chest X-ray, ultrasound liver, bone scan, liver-function tests, and Ca125/Ca153 analysis also performed within 3 months prior to surgery.

The participation rate was 75% ($n = 97$). Data of 15 women were excluded from the analyses because less than 75% of the items on the questionnaires were filled out. Based on clinical experience, we expected different levels and courses of distress for women who opted for PM or for PSO. Therefore, the sample was subdivided into a PM and a PSO group. Four women, having PSO first, opted for PM within 3–9 months during the follow-up period of the study. In view of the difficulty to attribute their responses to either one of the types of prophylactic surgery, their data were not used in the analyses. So, the final sample included 78 participants.

Physicians introduced the study to eligible patients with verbal and written information. After written informed consent, the participants received questionnaires by mail 2–4 weeks before (T0), and 6 and 12 months after prophylactic surgery (T1 and T2, respectively). The questionnaire included demographic data, and self-rating scales on general[25] and cancer-related[26] distress. The self-rating scales were administered at every measurement moment. The results of in-depth interviews, conducted at T0, T1 and T2, are not included in this analysis.

### 2.2. Reference group

To interpret the levels of distress before surgery, women with comparable increased risks, but opting for regular screening, were selected as a reference group. They participated in a national, prospective study (MRISC study) investigating the va-

lue of the magnetic resonance imaging scan (MRI).[27] The surveillance programme consisted of a physical examination twice a year, a mammography and MRI once a year within a 6-weeks period, while women were advised to perform breast self examination (BSE) once a month. For comparison with the PM/PSO group, we used the day of the control visit at the clinic as we assumed this moment as the most stressful during the surveillance period. All complete data sets of women who participated in that particular measurement moment were selected for reference, resulting in a 2:1 ratio of either mutation carriers ($n_{prevom} = 54 : n_{mrisc} = 27$) and a 1:7 ratio of risk carriers ($n_{prevom} = 24 : n_{mrisc} = 170$) from HBOC-families. Identical self-rating scales were used to assess psychological distress.

## 3. Methods

### 3.1. *Procedure of dividing the study sample into a PM and a PSO group*

Of all women in our sample, 34 opted for merely PM and 18 for merely PSO. The remaining 26 women could be divided into five separate categories:

1. PM and PSO were performed simultaneously ($n = 9$);
2. the participant was included before PM, and had undergone PSO prior to PM ($n = 7$);
3. the participant was included before PM, and underwent PSO during or after the follow-up period of the study ($n = 1$);
4. the participant was included before PSO, and had undergone PM prior to PSO ($n = 5$);
5. the participant was included before PSO, and underwent PM during or after the follow-up period of the study ($n = 4$).

For statistical reasons, we did not want to exclude this heterogeneous group, nor view it as a separate group. Therefore, we assigned participants to one of the groups based on the time elapsed between both types of surgery. We assumed that PM would have a greater physical and psychological impact than PSO. PM and PSO are different types of surgery regarding the impact on body image, cosmesis, and morbidity. Moreover, PSO is mostly performed in women above 40, who are generally in a different phase of their lives as compared to the women who opted for PM.

Therefore, participants who were included in the study because of PM and who underwent PSO prior to ($n = 7$), simultaneously ($n = 9$) or in the year after PM ($n = 1$), were classified in the PM group. For women who were assigned to categories 2 and 3, the time that had elapsed between both types of prophylactic surgery varied between 6.5 and 65 months, with an average of 26 months.

One participant, who underwent PM within two months after PSO, was included in the PM group.

The remaining participants of categories 4 and 5 ($n = 8$) were assigned to the PSO group. For these women, the time that had elapsed between both types of prophylactic surgery varied between 12 and 41 months, with an average of 24 months.

### 3.2. *Descriptive variables*

#### 3.2.1. *Biographical and medical data*

Age, marital status, offspring, religious affiliation, educational level, profession, carrier status, history of breast cancer, and type of surgery were recorded at T0.

### 3.3. *Outcome variables*

#### 3.3.1. *Cancer-related distress*

The impact of events scale (IES) is an established instrument[26,28–30] for measuring feeling overwhelmed by intrusive and avoidant thoughts, and feelings related to a traumatic event, and the tendency to adapt one's behaviour to these thoughts and feelings. In our study, these thoughts, feelings and behaviour were anchored to breast- and/or ovarian cancer. The response categories are not at all (0); seldom (1); sometimes (3); and often (5). The score range for the intrusion scale is 0–35 and for the avoidance scale 0–40. Reliability and validity are satisfactory.[28–31] No norms or cutoff scores are available for the general population. However, from two studies conducted in a clinical setting,[32,33] cutoff scores equal or higher than 13 on the intrusion subscale and equal or higher than 11 on the avoidance subscale were reported to be clinically relevant. In the present study, these cutoff values were considered as clinically significant.

### 3.4. *General distress*

General distress was measured with the hospital anxiety and depression scale (HADS).[25] The HADS has two scales for anxiety and depression, respectively. Every item has four response categories, anchored to that specific item. The scores range from 0 to 21 for both scales. Validity and reliability have proven to be sufficient.[34,35] A score between 8 and 10 on each subscale represents a doubtful case of either anxiety or depression. A score of 11 or higher per subscale is indicative of a clinically relevant level of distress.

### 3.5. *Statistical analysis*

The data were analysed using the SPSS 11.0 statistical package (SPSS Inc., Chicago). Missing values were estimated through multiple imputation. Frequency analysis was used to determine the characteristics of the participants and to calculate means for each subscale per group. Univariate analysis of variance determined differences on biographical variables and medical variables. *T*-test for independent samples was used to test for differences between the study sample and the reference group. Finally, MANOVA was used to determine whether the courses between the PM group and the PSO group were different. When the courses turned out to be different, it was tested whether the courses differed linearly and/or quadratically. A quadratic course means that the in-between assessment differed from the straight line between the first and the final assessment. All statistical testing took place at 0.05 level of significance (two-sided).

## 4. Results

### 4.1. Patients characteristics

The characteristics of all respondents, and the PM and PSO group separately are shown in Table 1. Both groups were identical on most biographical and medical data, except that women in the PM group were significantly younger than women in the PSO group ($p < 0.001$).

### 4.2. Baseline levels of distress between the study sample and the reference group

Table 2 presents the baseline levels on the outcome variables of the IES and the HADS in women who opted for prophylactic surgery (PREVOM-B study, this study) and women who adhered to regular breast cancer surveillance (MRISC-study). The samples only differed on carrier status. The PREVOM-group comprises twice as much mutation carriers than the MRISC-group, whereas the MRISC-group consisted of seven times as much risk carriers. The samples differed significantly on all measures of distress, whereby the women in the PREVOM-B study consistently had a higher score on the distress variables.

### 4.3. Comparison of the levels and course of distress between the PM and the PSO group

Table 3 presents the means, medians, ranges, and standard deviations of cancer-related and general distress in the PM and PSO group, at baseline, T1 and T2, respectively. Also, the courses per subscale and the relations between the groups on the means per subscale and over time are shown in Table 3, and are graphically shown in Fig. 1.

**Table 1 – Characteristics of the study population (SP; $n = 78$), the prophylactic mastectomy group (PM; $n = 52$) and the prophylactic salpingo-oophorectomy group (PSO; $n = 26$)**

| | SP ($n = 78$) | | PM ($n = 52$) | | PSO ($n = 26$) | | PM ↔ PSO |
|---|---|---|---|---|---|---|---|
| | M[a] | SD | M | SD | M | SD | $p$ |
| Age (in years) | 43 | 8.6 | 40 | 8.0 | 47 | 7.6 | 0.001 |
| | Range | | Range | | Range | | |
| | 25–63 | | 25–60 | | 34–63 | | |
| | $n$ | % | $n$ | % | $n$ | % | $p$ |
| *Marital status* | | | | | | | |
| Married or co-habiting | 69 | 89 | 45 | 87 | 24 | 92 | 0.78 |
| Single or divorced | 9 | 11 | 7 | 13 | 2 | 8 | |
| *Children* | | | | | | | |
| Yes | 64 | 82 | 41 | 79 | 23 | 88 | 0.30 |
| No | 14 | 18 | 11 | 21 | 3 | 12 | |
| *Religious* | | | | | | | |
| Yes | 31 | 40 | 19 | 37 | 12 | 46 | 0.42 |
| No | 47 | 60 | 33 | 63 | 14 | 54 | |
| *Education* | | | | | | | |
| Low/average | 59 | 76 | 42 | 81 | 17 | 65 | 0.09 |
| High | 18 | 23 | 10 | 19 | 8 | 31 | |
| Missing | 1 | 1 | – | – | 1 | 4 | |
| *Current job* | | | | | | | |
| Yes | 53 | 68 | 37 | 71 | 16 | 62 | 0.40 |
| No | 25 | 32 | 15 | 29 | 10 | 39 | |
| *Carrier status* | | | | | | | |
| Mutation carrier | 54 | 69 | 36 | 69 | 18 | 69 | 1.00 |
| Risk carrier | 24 | 31 | 16 | 31 | 8 | 31 | |
| *History of cancer* | | | | | | | |
| No | 50 | 64 | 35 | 67 | 15 | 58 | 0.54 |
| Breast cancer | 27 | 35 | 16 | 31 | 11 | 42 | |
| Ovarian cancer | 1 | 1 | 1 | 2 | – | – | |
| *Type of surgery* | | | | | | | |
| PM | 34 | 44 | 34 | 66 | – | – | 0.04 |
| PSO | 18 | 23 | – | – | 18 | 69 | |
| PM + PSO | 9 | 11 | 9 | 17 | – | – | |
| PM prior to PSO | 6 | 8 | 1 | 2 | 5 | 19 | |
| PM after PSO | 11 | 14 | 8 | 15 | 3 | 12 | |

a M = mean.

**Table 2 – Baseline levels on the impact of events scale (IES) and the hospital anxiety and depression scale (HADS) of women who opt for prophylactic surgery (PREVOM-study) and women who opt for regular surveillance (MRISC-study)**

| | PREVOM-study | | | MRISC-study | | | |
|---|---|---|---|---|---|---|---|
| | *n* | M[a] | SD | *n* | M | SD | *p* |
| *General distress* | | | | | | | |
| Anxiety | 78 | 6.4 | 4.4 | 197 | 5.1 | 3.9 | 0.02 |
| Depression | 78 | 3.7 | 3.5 | 197 | 2.6 | 3.0 | 0.01 |
| *Cancer-related distress* | | | | | | | |
| Intrusion | 78 | 10.6 | 8.9 | 197 | 5.1 | 6.4 | <0.001 |
| Avoidance | 78 | 9.4 | 8.4 | 197 | 4.5 | 6.3 | <0.001 |

a *M*, = mean.

In the PM group, intrusion, avoidance and anxiety showed a significant linear decrease over time. However, in the PSO group, no significant changes in the distress levels were observed before and after surgery.

### 4.4. *Clinical 'cases' of distress*

Table 4 shows the clinically relevant cutoff scores per subscale, the percentages per group of women who scored above these cutoff scores, as well as the mean scores for this subgroup on each measurement moment. The percentages of women scoring above the threshold value at either baseline or follow-up are also graphically illustrated in Fig. 2. At all time points, substantial percentages of women scored above the cutoff point of both subscales of the IES and above the cutoff point of the anxiety subscale of the HADS. At one year follow-up, 10% of all women who opted for PM scored above the cutoff score on anxiety, and 6% scored clinically high on depression, compared to resp., 19% and 4%, in the group of women who opted for PSO. As for cancer-related distress, 19% of all women who opted for PM scored above the cutoff score on intrusion, and 20% scored clinically high on avoidance, compared to 27% and 22%, respectively, of the women who opted for PSO.

## 5. Discussion

The current paper describes the levels of general and cancer related distress and the courses of these measures in genetically predisposed women who opted for either PM or PSO up to 12 months after prophylactic surgery.

Firstly, we observed that the levels of distress were increased prior to surgery in our sample as compared to a reference group of women who opted for breast cancer surveillance. This might indicate that the women who opt for prophylactic surgery experienced overall more distress, which might have played a role in their decision for prophylactic surgery instead of surveillance. Of course, other factors, *e.g.* anxiety related to upcoming surgery, may have played a role in the observed difference. For instance, most of the women who opted for either PM or PSO were mutation carriers, whereas in the reference group the majority were risk carriers from HBOC families. Mutation carriers received information on a higher cancer risk assessment, and consequently on the option of PM/PSO. In addition, one can speculate that the women in the group who chose to undergo surgery might have had more experience with witnessing cancer and death of family members. An impressive family history may also influence the physician's advice to encourage the patient to undergo prophylactic surgery.

Our second research question concerned the levels and course of distress after prophylactic surgery. In the group as a whole, no increase in the measures of psychological distress was observed. In the women allocated to the PM group, even significant decreases were seen with respect to anxiety, avoidance and intrusion. This is in accordance with the findings in other studies.[13,15,18] Our results support our clinical impression that women can undergo this type of surgery without further developing emotional distress. The decline of distress in the PM group might indicate that PM has diminished the fear of getting cancer. Moreover, after PM no further breast self examination is needed, and consequently results in less direct physical confrontations with being at a high risk of developing breast cancer. In addition, the frequency of surveillance at the clinic is diminished, and there is no further need for regular mammography and/or MRI examinations.

Contrary to earlier findings,[22] no measurable changes were found in the distress levels of women who underwent PSO. Again, this indicates that women can undergo this type of surgery without further developing emotional distress. The levels of distress in the PSO group were not exceptionally high prior to surgery, which might explain why distress did not decrease after PSO, as was observed in the PM group. Because the majority of women who underwent PSO were either nearing menopause or already postmenopausal, the physical consequences of this type of surgery might not have been of importance with respect to the decision for PSO. Moreover, the women who underwent PSO were older and in a different phase of their lives as compared to the women who opted for PM. Starting a family and/or raising young children was no longer an issue in the PSO group.

Our third research question addressed the comparison of the PM group and the PSO group on both the levels and the courses of all measures of distress. Though the course of distress appeared to be different for the two groups, we could not demonstrate any significant differences between the mean scores of the PM and the PSO group. We speculate that this lack of significance is due to the small sample size, but doubt if investigating a larger group would yield relevant differences between these groups.

Finally, we explored the frequency of scores considered to indicate clinically relevant distress. Substantial percentages

**Table 3 – Course of general and cancer-related distress for the prophylactic mastectomy (PM) group ($n = 52$) and the prophylactic salpingo-oophorectomy (PSO) group ($n = 26$)**

| | PM group ($n = 52$) | | | | | | PSO group ($n = 26$) | | | | | | $p$ (means) | $p$ (time × type of surgery) | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Mean | Median | Range | SD | $p$ (time) | | Mean | Median | Range | SD | $p$ (time) | | | L | Q |
| | | | | | L[a] | Q[a] | | | | | L | Q | | | |
| *Hospital anxiety and depression scale: general distress* | | | | | | | | | | | | | | | |
| Anxiety | | | | | | | | | | | | | | | |
| T0 | 7.0 | 6 | 0–19 | 4.5 | <0.001 | ns | 5.1 | 5 | 0–12 | 3.9 | ns | ns | ns | 0.003 | ns |
| T1 | 4.6 | 4 | 0–15 | 3.8 | | | 5.3 | 5 | 0–12 | 3.7 | | | ns | | |
| T2 | 4.5 | 4 | 0–14 | 3.1 | | | 5.1 | 5 | 0–12 | 3.5 | | | ns | | |
| Depression | | | | | | | | | | | | | | | |
| T0 | 4.0 | 3 | 0–14 | 3.8 | ns | ns | 2.9 | 3 | 0–9 | 2.5 | ns | ns | ns | ns | ns |
| T1 | 3.0 | 2 | 0–14 | 3.1 | | | 3.0 | 3 | 0–9 | 2.6 | | | ns | | |
| T2 | 3.3 | 2 | 0–11 | 2.9 | | | 3.0 | 3 | 0–9 | 2.3 | | | ns | | |
| *Impact of events scale: cancer-related distress* | | | | | | | | | | | | | | | |
| Intrusion | | | | | | | | | | | | | | | |
| T0 | 11.6 | 9 | 0–35 | 9.3 | <0.001 | ns | 8.5 | 7 | 0–24 | 7.6 | ns | ns | ns | ns | ns |
| T1 | 6.7 | 4 | 0–31 | 7.1 | | | 6.6 | 6 | 0–23 | 6.4 | | | ns | | |
| T2 | 7.2 | 6 | 0–34 | 7.2 | | | 7.9 | 8 | 0–26 | 7.2 | | | ns | | |
| Avoidance | | | | | | | | | | | | | | | |
| T0 | 10.3 | 9 | 0–40 | 8.8 | <0.001 | ns | 7.5 | 6 | 0–23 | 7.1 | ns | ns | ns | 0.002 | ns |
| T1 | 7.2 | 5 | 0–34 | 8.4 | | | 8.0 | 8 | 0–36 | 8.8 | | | ns | | |
| T2 | 5.6 | 4 | 0–38 | 7.0 | | | 6.7 | 5 | 0–23 | 7.2 | | | ns | | |

a L = linear; Q = quadratic.

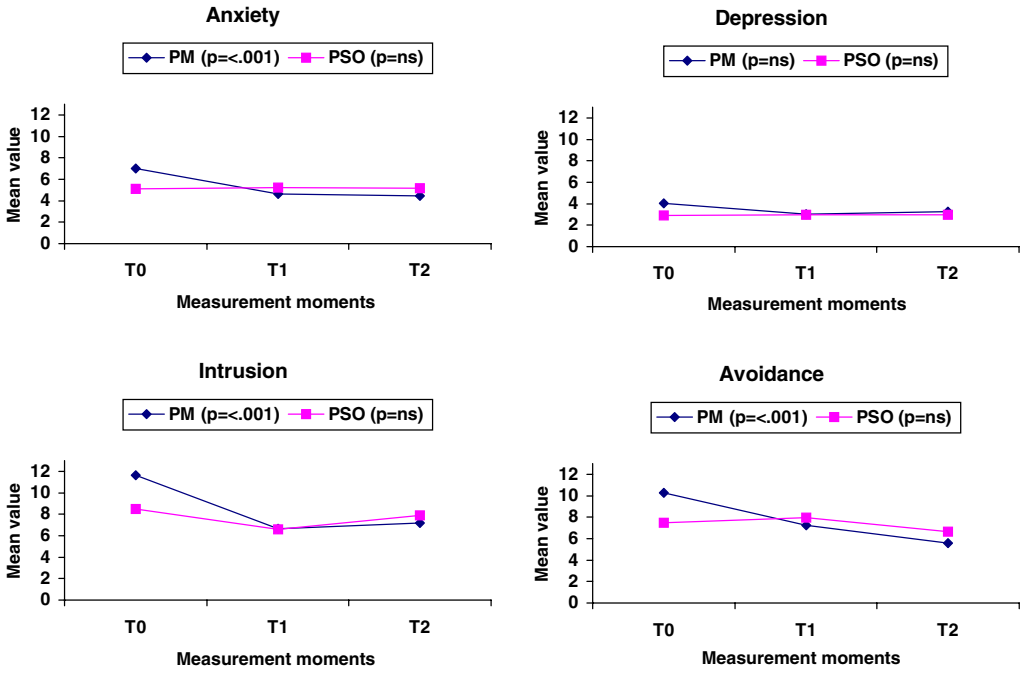


**Fig. 1 – Mean scores on the Hospital Anxiety and Depression Scale (HADS) and the Impact of Events Scale (IES) at baseline, 6 months follow-up and 12 months follow-up for women who opt for prophylactic mastectomy (PM; *n* = 52) and prophylactic salpingo-oophorectomy (PSO; *n* = 26).**

**Table 4 – Number, means and standard deviations of scores on intrusion, avoidance, anxiety and depression of women in the prophylactic mastectomy (PM) group and women in the prophylactic salpingo-oophorectomy (PSO) group, who scored above cutoff scores**

| | Cutoff | PM group (*n* = 52) | | | | PSO group (*n* = 26) | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | N | % | Mean | SD | N | % | Mean | SD |
| Hospital anxiety and depression scale | | | | | | | | | |
| *Anxiety* | | | | | | | | | |
| T0 | >8 | 13 | 26 | 13.6 | 2.8 | 6 | 22 | 10.3 | 1.2 |
| T1 | >8 | 9 | 18 | 10.9 | 2.1 | 5 | 19 | 10.6 | 1.1 |
| T2 | >8 | 5 | 10 | 11.0 | 2.3 | 5 | 19 | 10.3 | 1.5 |
| *Depression* | | | | | | | | | |
| T0 | >8 | 8 | 15 | 10.9 | 2.0 | 1 | 4 | 9.0 | – |
| T1 | >8 | 4 | 8 | 11.0 | 2.0 | 1 | 4 | 9.0 | – |
| T2 | >8 | 3 | 6 | 10.1 | 0.9 | 1 | 4 | 9.0 | – |
| Impact of events scale | | | | | | | | | |
| *Intrusion* | | | | | | | | | |
| T0 | >12 | 20 | 39 | 21.9 | 5.9 | 8 | 30 | 18.3 | 3.3 |
| T1 | >12 | 11 | 22 | 18.0 | 5.2 | 4 | 15 | 17.0 | 4.1 |
| T2 | >12 | 10 | 19 | 18.8 | 6.1 | 7 | 27 | 17.3 | 4.6 |
| *Avoidance* | | | | | | | | | |
| T0 | >10 | 21 | 41 | 18.6 | 7.8 | 8 | 30 | 16.3 | 4.3 |
| T1 | >10 | 10 | 20 | 21.4 | 8.8 | 11 | 41 | 15.7 | 7.8 |
| T2 | >10 | 10 | 20 | 16.5 | 8.1 | 6 | 22 | 18.0 | 3.3 |

of women at baseline and during follow-up scored in the clinical range of both subscales of the IES and the anxiety scale of the HADS. One explanation concerns the anchoring of the variables of the IES to breast and ovarian cancer. Intrusive thoughts on breast cancer might reflect one's concerns with the breast cancer process in relatives, instead of the personal risks. This explanation is supported by the findings of Van Dooren and colleagues,[36] who found that high scores on the IES around surveillance appointments were related to the involvement in the care for relatives with cancer. Another explanation is that having children or lacking a stable partnership can cause increased distress after prophylactic sur-

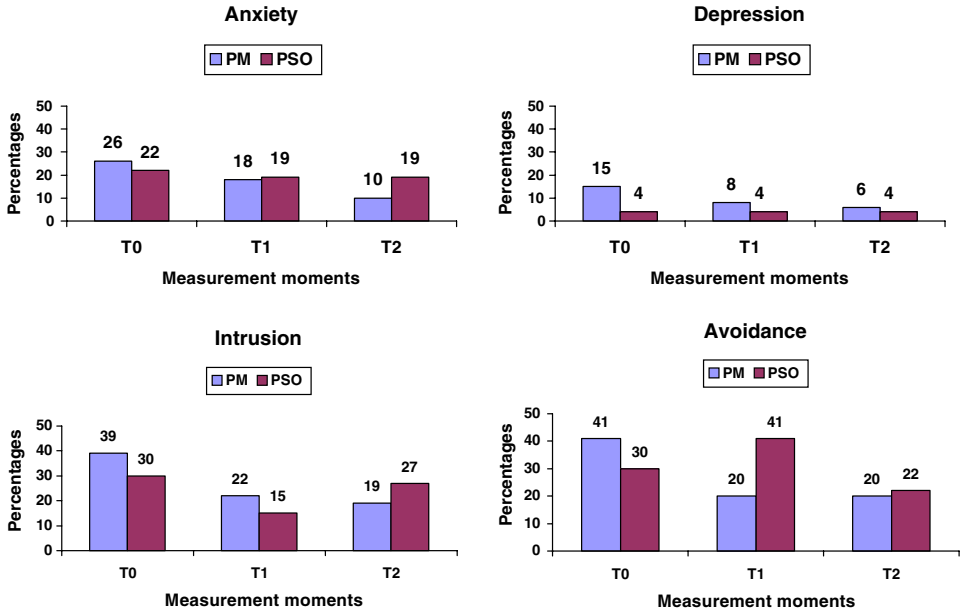


**Fig. 2 – Percentages of women in the prophylactic mastectomy (PM) group and the prophylactic salpingo-oophorectomy (PSO) group who scored above the cutoff score of the Hospital Anxiety and Depression Scale (HADS) and the Impact of Events Scale (IES) at baseline, 6 months follow-up and 12 months follow-up.**

gery, as was found in an earlier follow-up study done in our institute.[37] Further analyses of factors that are predicting enhanced scores on distress are in progress.

Our study could be criticised for the allocation procedure of women who had had both types of surgery to either the PM or the PSO group. Firstly, the allocation procedure was based on several clinical grounds, as was described in Section 3. Secondly, exploratory analyses of subsamples of different types of surgery allowed us to avoid splitting up the group into too many subgroups with a subsequent decrease in size. One could doubt whether and to which degree the decrease in distress observed at follow-up was coupled to PM. However, in our view this should not divert attention from our main finding, being that this type of surgery does not appear to induce psychological distress.

To our knowledge, our study is the first to present prospective data from a group of high-risk women opting for prophylactic surgery. It provides an insight into the level and course of general and cancer-related distress of women who opt for PM compared to women who opt for PSO. Moreover, the distress levels of women who opted for prophylactic surgery are compared to the distress levels of women who opted for regular surveillance.

Prophylactic surgery is an irreversible procedure that is performed in healthy high-risk women on parts of the body that conceivably are related to self-image, sexual attractivity and perception, etc. Our results show that women can undergo this type of surgery without developing emotional distress to a relevant degree. Further, prophylactic mastectomy even appeared to decrease distress to some degree. More research is needed to further define the characteristics of the women who continue to have clinically relevant increased scores after surgery, in order to identify them and offer them additional counselling. So far, we suggest inclusion of a referral to a psychologist or psychosocial worker as part of the preoperative work up for women considering a PM.

## Conflict of interest statement

None declared.

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