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## Body image and psychological distress after prophylactic mastectomy and breast reconstruction in genetically predisposed women: A prospective long-term follow-up study

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### ABSTRACT

**Purpose:** To explore the course of psychological distress and body image at long-term follow-up (6–9 years) after prophylactic mastectomy and breast reconstruction (PM/BR) in women at risk for hereditary breast cancer, and to identify pre-PM risk factors for poor body image on the long-term.

**Methods:** Psychological distress (general and breast cancer specific) and body image (general and breast specific) were assessed in 36 high-risk women before PM (T0), at 6 months (T1) and 6–9 years (T2) after PM/BR. Investigated predictive variables (assessed at T0) for long-term body image (assessed at T2) included psychological distress, body image and coping styles.

**Results:** Breast cancer specific and general distress significantly decreased from T0 to T1 as well as from T1 to T2. Problems regarding breast related and general body image were significantly higher at T1 than at T0. Subsequently, breast related body image scores significantly decreased from T1 to T2, while the decrease in general body image scores were not significant. Active coping and seeking social support were predictive of lower scores (i.e. less problems) on breast related and general body image at long-term follow-up. Furthermore, higher scores on general body image before PM/BR were predictive for increased general body image scores at long-term follow-up.

**Conclusion:** Our findings indicate that psychological distress is decreased after PM/BR, at the cost of persistent problems regarding body image. Exploration of coping styles and body image perception before PM/BR may help to identify vulnerable women who may benefit from additional support.

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## 1. Introduction

At this moment, bilateral or contralateral prophylactic mastectomy with or without breast reconstruction (PM/BR) is the most effective, although radical, strategy to reduce the risk of breast cancer in high-risk women.<sup>1–3</sup> As DNA-testing becomes more readily available and cosmetic results of reconstruction techniques are improving, PM has become an important and recognised option for women at risk for hereditary breast cancer. Balanced information regarding long-term psychological outcomes therefore is eagerly needed in order to enable adequate counselling of women considering PM/BR.

Overall, women at risk for hereditary breast cancer who have undergone PM are satisfied with their decision.<sup>4–6</sup> Several studies concluded that PM may have psychological benefits in terms of reduced anxiety and worries about developing cancer.<sup>5,7–10</sup> Nevertheless, many women included in the studies reported negative effects of PM(/BR) on body image.<sup>5,6,10,11</sup> However, as most of these observations were obtained from retrospective studies, information on women's body image prior to PM is not available, and consequently changes in body image specifically as a result of PM/BR could not be assessed.

So far, prospective studies examining the effects of PM on psychological variables and body image have been scarce.<sup>11</sup> One prospective, qualitative study reported reduced anxiety 18 months after PM, while no evidence was found for body image problems.<sup>8</sup> In two other prospective studies with a follow-up of 1 year, reduced anxiety in women after PM was confirmed, while, in contrast, a substantial proportion of the women reported body image problems after 1 year.<sup>10,12</sup> However, it may be that a follow-up period of 1 year was too short to capture the assimilation of reconstructed breasts into a woman's body image, especially in view of the fact that the breast reconstruction period (depending on the reconstruction technique) may encompass several months. Therefore, longer follow-up data are needed on the psychological adjustment to PM/BR, especially regarding body image. Furthermore, no data are available on factors that are predictive of poor body image after PM/BR. Knowledge about these factors is important in order to enable early identification of women who may be vulnerable, and might benefit from additional support.

In the present prospective study, we aimed (1) to explore the course of psychological distress and problems regarding body image before PM and at long-term follow-up (6–9 years) after PM/BR in women at risk for hereditary breast cancer, and (2) to identify pre-PM variables being predictive of poor body image in the long term.

## 2. Patients and Methods

### 2.1. Participants

Between 1999 and 2003, women at risk for hereditary breast/ovarian cancer who decided to undergo prophylactic mastectomy (PM) with/without BR or bilateral salpingo-ovariectomy (BPSO) at the Family Cancer Clinic of the Erasmus MC – Dan-

iel den Hoed Cancer Centre were invited to participate in a study on the psychological impact of prophylactic surgery (PREVOM-B study). A history of breast or ovarian cancer was not an exclusion criterion, but women with (suspicion of) new or recurrent cancer were not eligible. Detailed descriptions of the PREVOM-B study have been published elsewhere.<sup>7,13</sup>

In 2007, a follow-up study was activated investigating the long-term psychological impact (i.e. between 6 and 9 years since enrollment in the PREVOM-B study) of prophylactic surgery in high-risk women. Women were eligible for the follow-up study if they had participated in PREVOM-B, had not developed a new cancer or recurrent cancer since enrollment in the PREVOM-B study, and still were in follow-up at the family cancer clinic of the Erasmus MC. Women had sufficient understanding of the Dutch language to fill in the questionnaires and all gave informed consent for the follow-up study. Approval for the follow-up study was obtained from the Medical Ethics Committee of the Erasmus Medical Center in Rotterdam.

### 2.2. Procedure

Women having participated in the PREVOM-B study and having undergone PM/BR were sent an information letter regarding the psychological follow-up study along with an informed consent form and a prepaid envelope. After receipt of written informed consent, women were sent the first questionnaire of this follow-up study to their home address 2 months prior to the next appointment at the family cancer clinic. The analyses for the current report were carried out on the data obtained from the following assessment moments: 2–4 weeks before PM/BR (T0), at 6 months after (T1) and 6–9 years after (T2) PM/BR.

### 2.3. Measurements

#### 2.3.1. Biographical and medical data

Data on age, having a partner, having children, educational level, carrier status and breast cancer history were obtained by means of a questionnaire completed at both T0 and T2.

#### 2.3.2. Coping

Coping was assessed at T0 with the Utrecht Coping List (UCL).<sup>14</sup> The UCL is a 48-item questionnaire, measuring seven coping styles: Active Approach, Palliative Reaction, Avoidance, Seeking Social Support, Passive Coping, Emotional Expression and Comforting Thoughts. Previous studies revealed satisfying validity and reliability measures of the UCL.<sup>15,16</sup>

#### 2.3.3. Psychological distress

At all assessment moments (T0, T1 and T2) women completed the Impact of Events Scale (IES)<sup>17</sup> and the Hospital Anxiety and Depression Scale (HADS),<sup>18</sup> measuring breast cancer specific distress and general distress, respectively. Both scales have been described in detail elsewhere.<sup>19</sup>

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