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CHAPTER 7 BODY IMAGE ISSUES AFTER BILATERAL PROPHYLACTIC MASTECTOMY WITH BREAST RECONSTRUCTION IN HEALTHY WOMEN AT RISK FOR HEREDITARY BREAST CANCER

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Abstract

Objective The outcome of bilateral prophylactic mastectomy with breast reconstruction (BPM-IBR) in healthy BRCA1/2 mutation carriers can be potentially burdensome for body image and the intimate relationship. Therefore, in the current analysis the impact on body image, sexual and partner relationship satisfaction was prospectively investigated in women opting for BPM-IBR as well as cancer distress and general quality of life.

Methods Healthy women undergoing BPM-IBR completed questionnaires preoperatively (T0, n=48), at 6 months (T1, n=44) and after finishing breast reconstruction (median 21 months, range 12-35) (T2, n=36). With multi-level regression analyses the course of outcome variables was investigated and a statistically significant change in body image and/or sexual and partner relationship satisfaction was predicted by baseline covariates.

Results Body image significantly decreased at T1. At T2 sexual relationship satisfaction and body image tended to be lower compared to baseline. The overall partner relationship satisfaction did not significantly change. At T2, 37% of the women reported that their breasts felt unpleasantly, 29% was not satisfied with their breast appearance and 21% felt embarrassed for their naked body. Most body image issues remained unchanged in 30% of the women. A negative body image was predicted by high preoperative cancer distress.

Conclusions BPM-IBR was associated with adverse impact on body image in a substantial subgroup, but satisfaction with the overall sexual and partner relationship did not significantly change in time. The psychosocial impact of BPM-IBR in unaffected women should not be underestimated. Psychological support should ideally be integrated both before and after BPM-IBR.

Introduction

Women with a BRCA1/2 mutation have a significantly increased cumulative lifetime risk for developing breast cancer (39-85%) as well as ovarian cancer (10-63%) [1-3]. One of the risk reducing strategies for developing breast cancer is bilateral prophylactic mastectomy usually including immediate breast reconstruction (BPM-IBR), which is associated with a risk reduction of more than 90% [4-6]. The decision for BPM-IBR among healthy BRCA mutation carriers in the Netherlands (33%) is one of the highest in the world, in line with data from the USA (36%) and the UK (40%) [7;8].

After BPM-IBR, women report reduced cancer distress and anxiety, at the cost however of potentially negative impact on body image and the intimate relationship [9-18]. Drawbacks of the previously reported studies are a retrospective design [10;12;15;19], and for the few available prospective studies performed in unaffected BRCA1/2 mutation carriers a limited follow-up period, maximally being up to one year postoperatively [9;14;16;20]. The single, prospective, long term follow-up study on the impact of prophylactic mastectomy with or without breast reconstruction included both *unaffected and affected* (history of breast and/or ovarian cancer) female BRCA mutation carriers (n=36), and showed ongoing problems with body image up to 6 to 9 years after PM/BR [11].

In the current study we focused on *unaffected* women, as the life event of having cancer may significantly disrupt quality of life, and more specifically the impact of BPM-IBR. We aimed to prospectively explore the course of 1) body image, and of satisfaction with the sexual and partner relationship, as well as of 2) cancer distress, and health related quality of life in women opting for BPM-IBR. The final assessment was planned after completion of the breast reconstruction process.

Methods

Patients

This study is part of a multicenter prospective follow-up study on the psychological impact of breast reconstruction, which was performed in both academic and regional hospitals in the Netherlands [21-23]. For the current analyses, participants were healthy (=unaffected) women at significantly increased risk of breast cancer due to a BRCA mutation or relevant family history who had opted for BPM-IBR. Exclusion criteria were suspicion of breast cancer in the planning towards BPM and a detection of breast cancer in the follow-up, and not being able to understand and speak the Dutch language sufficiently. Patients were approached between December 2007 and May 2010, and ethics approval was obtained from all participating hospitals⁵.

Seventy-three unaffected high-risk women scheduled for BPM-IBR were invited for the study by written information (academic hospitals: n=71, regional hospitals: n=2) and 50 women consented to participate (68%) (academic hospitals: n= 48, regional hospitals: n=2).

⁵ Leiden University Medical Center (LUMC), Erasmus University Medical Center Rotterdam (Erasmus MC), Daniel den Hoed Cancer Centre, Haga Teaching Hospital (Haga), Admiraal de Ruyter Hospital Goes.

Procedure

The invitation procedure has been described elsewhere [23]. Patients who returned informed consent, received the study questionnaires which they were requested to fill in preoperatively (T0). Similar questionnaires were sent at six months after BPM-IBR (T1), and after completing the BR process (T2). If BR was not completely finished (nipple reconstruction and/or nipple areola complex tattooing were planned but not yet performed) at the end of the follow-up period of the study, the final T2 questionnaire was still sent to measure the result at longer follow-up. The median follow-up time at T2 was 20.7 months, (mean = 21.7 months, range 12-35 months).

A maximum of two reminders were sent by letter if patients did not respond at T1 and/or T2, and patients were requested to provide a reason for non-compliance.

At least 75% of the respective questionnaires had to be filled in to calculate a scale score.

Measurements

Demographic information and clinical data were assessed with questionnaires and medical data were confirmed by checking medical records.

Primary outcome measures

Body image

We developed a study-specific body image scale (BIS) based on the Body Image/Sexuality questionnaire of Lodder et al. [24], who followed recommendations made by Cull [25] and Hopwood [26]. For conceptual reasons some items were adapted regarding the specific experience of going to the beach in bathing clothes, feeling comfortable in V-necked clothes, feeling comfortable when touched by the partner and feeling embarrassed when getting undressed in the partner's presence. The questionnaire consists of 31 items regarding the "past three months" which are scored on a five-point Likert scale. An explorative principal component analysis was performed in a large sample of women with therapeutic and/or prophylactic mastectomy with breast reconstruction, who had completed the questionnaire at multiple time points (n=442). Using the Scree-test criterion, we found a three-factor solution that accounted for 49.5% of the total variance. Items loading on one component exceeding 0.40 were considered to belong to a subscale. With a loading on two factors a difference of at least 0.09 was used.

The three-factor solution revealed three components of the 31 items: 1) a subscale measuring body image aspects (BIS-BIM) consisting of 13 items (see Table 4, explaining 19.8% of the total variance); 2) a subscale measuring the general importance of appearance (3 items, 7.6% of total variance, not shown); 3) a subscale measuring problems with intimacy (15 items, 22.1% of the total variance, not shown). For this study, only the first subscale, BIS-BIM, was used and the internal consistency of this subscale (13 items) proved to be good in the current study sample (Cronbach's $\alpha = 0.89$). The items were scored from 1-5 (totally disagree, disagree, neutral, agree, totally agree, respectively) and a mean scale score was calculated (1-5), where a higher score indicates a more positive body image. Two items

(12 and 13, see Table 4) were only completed by patients with a partner, however, for the single women a mean scale score was calculated as well as at least 75% (10 items) had to be completed.

To explore the occurrence of body image problems, items of the subscale BIS-BIM were recoded into three categories: 1 'disagree' (=1 and 2); 2 'neutral' (=3); 3 'agree' (=4 and 5) and relevant categories were reported in Table 4.

Satisfaction with the sexual relationship

Satisfaction with the *sexual relationship* was measured using the subscale 'sexuality' of the Dutch Relationship Questionnaire (Nederlandse Relatie Vragenlijst, NRV) including 11 items [27]. The NRV has shown good psychometric properties, and a total score on the subscale 'sexuality' below eight (range 0-12) indicates below average or low satisfaction with the sexual relationship and a bad sexual compatibility with the partner [27]. The NRV was completed only by patients having a partner.

Satisfaction with the overall partner relationship

Satisfaction with the overall partner relationship was investigated with the NRV as well (again only for patients with a partner). Normally, the total score of the NRV can be used to provide this satisfaction score. However, to correct for the impact of sexuality, the score of the 'sexuality' subscale was subtracted from the total score. Therefore, scores under 49 (range 0-68) indicate below average or low satisfaction with the partner relationship, excluding sexuality.

Secondary outcome measures

General physical and mental health were assessed with the Dutch version of the 36-item Short-Form Health Survey (SF-36) with respectively the Physical Component Summary (PCS) and the Mental Component Summary (MCS) of the SF-36 [28-30]. These scales concerned e.g. physical functioning, social functioning, vitality and bodily pain. In this norm based scoring method each scale has the same mean value (50) and standard deviation (10). Consequently, a scale score below 50 indicates that health status is below average [29].

Breast cancer specific distress was measured using the 15-items Impact of Event Scale (IES) [31;32]. The total IES score was used in this study with a range from 0 to 75. Reported reliability and validity of the IES are satisfactory [31;33]. The categorization of the IES score is not indicative for specific clinical diagnoses, but a cutoff score of 20 or higher can be used to indicate high symptom levels [33;34].

Statistical analyses

To investigate changes in time in the primary and secondary psychological outcomes, multi-level regression analyses (MLA) were performed, which can handle incomplete time-series data efficiently with a minimal loss of information. These analyses also compensate for different numbers of participants at each time point.

For the analyses of the time-course linear and quadratic time were included as covariates in the regression models. Effect sizes [35] were calculated by dividing the estimated differences by the estimated standard deviation at baseline. For the determination of body image course predictors a two-step procedure was applied. In the first step the number of potential covariates to be used in the MLA was reduced by calculating change scores between T0 and T1, and T0 and T2 and consequently by calculating their Spearman's Rho correlation coefficients with regard to age, having a partner, having children, type of BR, body mass index (BMI), having had prophylactic bilateral salpingo-oophorectomy (PBSO), the relationship with self-reported severe postoperative complications (=complications that lead to an unfinished result or removal of the reconstructed breast mound) and with the baseline psychological variables⁶. We applied a lenient p-value in order not to exclude covariates unduly, therefore the variables that correlated with the change scores ($p < 0.10$), were entered in the MLA. Continuous covariates were standardized to facilitate the interpretation of the estimates.

In a backward procedure all non-significant effects were removed from the model, until a parsimonious model was reached ($p\text{-out} > 0.10$). It was taken into account that interaction effects should be nested within the respective main effects [36]. The deviance statistic, that is the difference between the -2 residual log Likelihood fit measure of the final parsimonious model and the fit of the saturated model [37], was evaluated at a $p = 0.05$ level.

Finally, changes in proportions of the BIS-BIM-items (agree / disagree) in time were explored with the Cochran's Q-test in which the p-value represented a change in time (T0 / T1 / T2) in a related sample. Two-sided p-values $< .05$ were considered statistically significant and data were analyzed with the statistical package SPSS 17.0 (SPSS Inc., Chicago).

Results

Patient samples

Non-respondents ($n = 23$) and respondents ($n = 50$) did not significantly differ in age ($t_{(70)} = 0.77$, $p=0.44$). However, all non-respondents opted for implant BR compared to 19% of the respondents who chose DIEP flap BR (Fischer's Exact test, $p = 0.025$).

Two patients were excluded from further analyses as breast cancer was unexpectedly found in the mastectomy specimens. Seven women stopped participation and nine women did not respond at T1 and/or T2 regarding at least one of the questionnaires (Figure 1)⁷. Drop-out analysis was performed comparing these 16 patients with the 32 women with 100% response rate at all questionnaires during follow-up (Figure 1)⁸. Dropouts less often had a partner (69% vs 97%, Fisher's Exact test $p=0.012$), and reported a significantly lower sexual satisfaction level at baseline (mean=7.2, sd=3.3) compared to the active participants (mean=9.5, sd=2.2) ($t_{(39)}=2.38$, $p=0.022$). More dropouts had an unfinished breast reconstruction at the end of the follow-up study (69% vs 31%, Fisher's Exact test

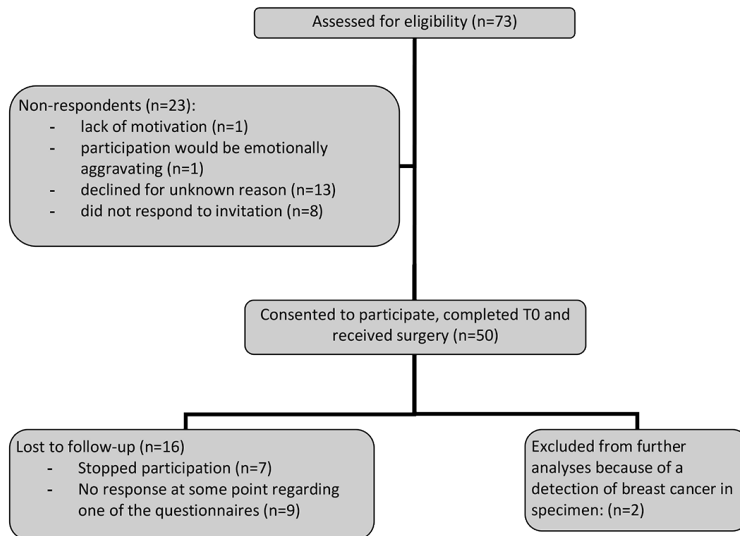
⁶ Correlation coefficients with body image change scores were calculated for the following baseline psychological variables: sexual and partner relationship satisfaction, cancer distress and general mental and physical health.

⁷ Dropout reasons: questionnaires were "too general" or "time consuming", having had complications, "there was no cancer distress as there was no cancer", and "not feeling psychologically stable"

⁸ Sexual and partner relationship satisfaction was only completed by women with a partner, therefore, N may be lower than 32 for these variables.

$p=0.001$). They did not differ significantly in the other medical, demographic and baseline psychological variables (data not shown).

Figure 1. Flow chart of patient inclusion



Demographic and clinical characteristics

Mean patient age of the study participants ($n=48$) was 37.1 years ($sd = 10.2$) yrs, range 21-65 yrs (Table 1). The majority had a partner ($n=42$) and children. Forty-four women were BRCA1/2 mutation carriers, one woman had an unclassified variant (UV), and three women opted for BPM-IBR based on the pedigree and risk estimation (belonging to non-BRCA1/2 mutation families)⁹. The minority (19%) underwent an autologous breast reconstruction with DIEP-flap (Table 1). Twenty-three percent had undergone PBSO at baseline and twelve women reported severe postoperative complications leading to an unfinished result or removal of the primary breast mound reconstruction.

Short term follow-up results from baseline (T0) to 6 months (T1) postoperatively

As shown in Table 2, a significantly less positive body image was detected at T1 compared to T0 ($p<0.001$). Satisfaction with the sexual as well as the overall partner relationship did not significantly change between T0 en T1, but sexual satisfaction tended to decrease ($p=0.07$). Cancer distress was above the cut-off score before surgery, and significantly decreased at T1 ($p<0.001$). General mental health at baseline was significantly improved at T1 ($p=0.02$). General physical health, at baseline significantly declined at T1 ($p<0.001$).

⁹ The four women without a BRCA1/2 mutation preferred PM over surveillance and after multidisciplinary consultation, they were allowed to have surgery.

Table 1. Baseline characteristics of 48 women opting for bilateral prophylactic mastectomy with immediate breast reconstruction (BPM-IBR)

Mean age in years at time of BPM-IBR (sd)	37.1 (10.2)
Having a partner	42 (87.5%)
Having children	31 (64.6%)
Education level	
primary education	10 (20.8%)
lower secondary education	20 (41.7%)
secondary and high education	18 (37.5%)
Breast cancer risk category	
BRCA1 carrier	33 (68.8%)
BRCA2 carrier	11 (22.9%)
Familial risk for breast cancer	4 (8.3%)
Type of breast reconstruction	
Implant	39 (81.3%)
DIEP-flap	9 (18.8%)
Mean BMI (sd)	25.1 (4.4)
Prophylactic bilateral salpingo-oophorectomy	11 (22.9%)
Severe complications*	12 (25.0%)

BMI: body mass index; DIEP: Deep Inferior Epigastric artery Perforator; SD: standard deviation; * self-reported severe complications that lead to an unfinished result or removal of the primary breast mound reconstruction

Longer term follow-up results from baseline (T0) to 21 months (T2) postoperatively

Body image and the sexual relationship satisfaction tended to decrease up to T2 (both $p=0.06$). The partner relationship satisfaction did not significantly change. Cancer distress significantly declined up to T2 ($p < 0.001$). For both general mental and physical health, the course did not significantly change from T0 to T2.

Predictors of a decreased body image after BPM-IBR

Correlation coefficients with the body image change scores ($p < 0.10$) revealed the following putative baseline covariates for body image (T0-T1; T0-T2): BMI ($r=0.28$, $p=0.07$, $n=44$ for T0-T1), cancer distress ($r=-.40$, $p=0.008$, $n=43$ for T0-T1; $r=-0.47$, $p=0.005$, $n=35$ for T0-T2) and general physical health ($r=-0.48$, $p=0.004$, $n=34$ for T0-T2). Therefore, BMI, baseline cancer distress and general physical health with their time interactions were entered into the saturated prediction model. Table 3 represents the final parsimonious model predicting the course of body image. It demonstrates that a preoperative cancer distress of 1 standard deviation higher than the average distress score leads to a decreased body image score of

Table 2. Psychosocial and psychosexual functioning before BPM-IBR, and 6 and 21 months postoperatively

	Parameter estimates			Time point estimates							
	Intercept	Time linear	Time quadratic	T1		T2		T0-T1		T0-T2	
				effect size	p	effect size	p	effect size	p	effect size	p
Body image (1-5) ^a	3.8****	-0.10****	0.0042****	3.3	3.5	-0.68	<0.001	-0.40	0.06		
Sexual relationship satisfaction α (0-12) ^b	9.0****	-0.10*	0.31	8.5	8.0	-0.19	0.07	-0.35	0.06		
Partner relationship satisfaction α (0-68) ^b	60****	-0.033	-0.0016	60	58	-0.03	0.79	-0.19	0.33		
Cancer distress (0-75) ^c	23****	-2.4****	0.091****	12	13	-0.82	<0.001	-0.74	<0.001		
General mental health ^d	48****	0.82**	-0.034**	51	50	0.38	0.02	0.23	0.19		
General physical health ^d	55****	-1.5****	0.068****	48	53	-0.64	<0.001	-0.16	0.37		

NOTE: the estimate for the intercept equals the estimate for T0. * p<0.10; ** p<0.05; *** p<0.001; **** p<0.001; BPM-IBR: bilateral prophylactic mastectomy and immediate breast reconstruction; T0: baseline assessment; T1: 6 months post-surgery; T2: 21 months post-surgery; ^aBody Image Scale; ^bDutch relationship questionnaire; ^cImpact of Event Scale; ^dShort Form – 36; α : completed only by patients with a partner; Higher scores indicate better outcomes, however for Cancer distress this is vice versa.

$6 \times -0.074 + 6 \times 6 \times 0.0033 = -0.33$ (Cohen's $d = -0.63$) at 6 months and a decrease of $21 \times -0.074 + 21 \times 21 \times 0.0033 = 0.10$ ($d = -.83$) at 21 months (Table 3). A high preoperative cancer distress score that leads to a more negative body image at long term follow-up applies to a quarter ($n=12$) of the women.

Furthermore, a higher preoperative general physical health predicted a better body image ($d=0.30$) and a lower BMI predicted a less positive body image ($d=-0.36$), in general, for women undergoing BPM-IBR.

Table 3. Predictors of the course of body image in women undergoing BPM-IBR

	Estimate [95% CI]	Std. Error	p-value
Intercept	3.76 [3.57 – 3.94]	0.09	<0.001
Time linear	-0.074 [-0.121 – -0.026]	0.024	0.003
Time quadratic	0.0033 [0.0011 – 0.0054]	0.0011	0.003
Preoperative cancer distress ^a	-0.118 [-0.304 – 0.067]	0.093	0.208
Time linear * preoperative cancer distress ^a	-0.076 [-0.124 – -0.028]	0.024	0.002
Time quadratic * preoperative cancer distress ^a	0.0025 [0.0004 – 0.0047]	0.0011	0.023
Preoperative general physical health ^b	0.172 [0.054 – 0.290]	0.059	0.005
BMI	-0.208 [-0.346 – -0.071]	0.068	0.004

BPM-IBR: bilateral prophylactic mastectomy and immediate breast reconstruction; ^aImpact of Event Scale; ^bSF-36: Short Form – 36; BMI: body mass index

Frequency of body image issues

Specific issues with body image are shown in Table 4 in which the items of the subscale BIS-BIM are presented. After BPM-IBR at T2, a significantly increased proportion ($p=0.001$) of women reported they were not happy with the appearance of their breasts (item 6, 29%) and the way their breasts felt (item 7, 37%), in particularly being the case at T1. At T1, a significant percentage did not feel feminine which was significantly higher compared to baseline and T2 ($p=0.02$).

For most items there was no significant change, substantial proportions remained having problems with their naked appearance (item 3, 20-30%), had trouble touching their breasts (item 5, 26-17%), felt sexually unattractive (item 8, 17-32%), were embarrassed for their naked body (item 11, 12-24%) and felt uncomfortable when the partner touched their breasts (item 12, 30-39%) before as well as after surgery.

Table 4. Number of women with body image problems before and after BPM-IBR regarding the “past three months” (BIS-BIM)

	T0		T1		T2		p-value*	
	N	%	n	%	n	%		
1. I was happy with my appearance when dressed [disagree]	36	2	5.6	3	8.3	4	11.1	0.69
2. I felt very feminine [disagree]	35	1	2.9	5	14.3	1	2.9	0.02
3. I was satisfied with my naked appearance [disagree]	35	7	20.0	12	34.3	11	31.4	0.20
4. I had trouble looking at my naked self [agree]	35	3	8.6	7	20.0	4	11.4	0.27
5. I had trouble touching my breasts [agree]	35	9	25.7	6	17.1	6	17.1	0.41
6. I was satisfied with the appearance of my breasts [disagree]	35	6	17.1	19	54.3	10	28.6	0.001
7. My breasts felt pleasantly [disagree]	35	7	20.0	21	60.0	13	37.1	0.001
8. I felt sexually attractive [disagree]	34	6	17.6	11	32.4	6	17.6	0.17
9. I felt comfortable enough to wear V-necked clothes [disagree]	35	3	8.6	5	14.3	7	20.0	0.30
10. I felt comfortable enough to wear swimwear [disagree]	35	3	8.6	8	22.8	4	11.4	0.05
11. I was embarrassed for my naked body [agree]	34	4	11.8	8	23.5	7	20.6	0.24
12 α . I felt comfortable when my partner touched my breasts [disagree]	23	8	34.8	9	39.1	7	30.4	0.65
13 α . I had qualms about getting undressed in the presence of my partner [agree]	30	1	3.3	6	20.0	5	16.7	0.07

BPM-IBR: bilateral prophylactic mastectomy with immediate breast reconstruction; BIS-BIM: body image subscale; T0: baseline assessment; T1: 6 months post-surgery; T2: 21 months post-surgery; * Cochran's Q test, overall difference in time. α : completed only by patients with a partner

Discussion

In women undergoing BPM-IBR mean body image scores decreased within the first 6 months after PM (T1), and it still tended to be lower after breast reconstruction (T2) compared to baseline. The mean scores of the partner relationship satisfaction did not significantly change in time, but the mean score of the sexual relationship satisfaction tended to decrease up to T2. When investigating specific body image issues on item level, we found that a substantial subgroup of the women reported problems after BPM-IBR, however, most issues already existed before surgery and did not change afterwards.

Comparing the number of women with body image issues in this study with corresponding samples of Lodder [24] and Den Heijer et al [11] the proportions of women with body image problems are similar. However, as there is a lack of body image data in a comparable age-matched healthy control group, we cannot tell how these proportions differ from the norm.

At 6 months, most women were in the middle of their breast reconstruction process. In particular women with implant breast reconstruction, who underwent a period of tissue expansion during the first months. At that point 55% was not satisfied with the appearance of their breasts. Although the majority had acceptable outcomes after BPM-IBR, the impact of BPM-IBR on body image and the intimate relationship should not be underestimated. There is a subgroup of patients at risk for developing a negative body image particularly during the breast reconstruction process (at T1) which should be taken into account during follow-up consults.

Our findings confirmed that prophylactic surgery results in a large reduction of cancer specific distress, which may be replaced by other problems, such as a decrease in physical health and a less positive body image during the BR process [9-18]. The total breast reconstruction course may cover a long period, up to 1.5 years, including expansion of tissue expanders, replacement with definite implants, additional aesthetic corrections and nipple reconstruction. After completion of breast reconstruction, physical health and body image may improve again.

It often happens that additional operations for complications or aesthetic reasons are needed after the primary breast mound reconstruction which is in accordance with our study findings [38-43]. Some women in this study experienced postoperative complications resulting in an unfinished result or poor breast reconstruction outcome. However, this was not related to a poorer body image, which can be possibly explained as a result of the small sample size. When calculating the change scores for the total observations (n=128) this variable indeed was negatively correlated with body image (data not shown).

It was an encouraging observation that the general mental health score improved significantly 6 months after BPM-IBR which might be explained by the initial relief from the reduction of the cancer risk due to the prophylactic mastectomy. Furthermore, the mean evaluation of the overall partner relationship remained stable and despite the tendency of a decline in the sexual relationship satisfaction, both mean NRV scores corresponded with normal norm scores [27]. Nevertheless, the trend towards a decline in sexual satisfaction, suggests that this finding could have been statistically significant in a larger sample.

A limitation of our study may be that no sexual *dysfunction* scale was included. A planned follow-up study shall provide more information about the issues in women with BPM-IBR regarding sexual dysfunction. We expect that sexual function might also be affected due to the consequences of (future) premenopausal PBSO, which is generally advised in BRCA1/2 mutation carriers [44;45]. This may result in adverse psychological, somatic and sexual consequences (e.g. vasomotor symptoms, vaginal dryness, decreased libido) [46-48]. Furthermore, future studies should include a validated breast reconstruction-specific questionnaire as well, such as the Breast-Q [49] for which norm data should be available as well to compare body image scores with a healthy age-matched norm group.

The study sample size was small; therefore MLA offered the best opportunity to analyze the data to correct for dropouts who had earlier reported worse scores on the psychological variables. An unfinished breast reconstruction procedure may have reinforced dropping out, as the dropout rate was significantly higher in this group. The full response rate on the body image questionnaire however, was high (75%), whereas it was lower for some of the other questionnaires (minimum response rate 67%). One of the reasons for this difference may be a lack of motivation to complete a whole battery of questionnaires. Some women had stated they did not want to complete the IES as they “did not have cancer and therefore did not have cancer distress”. Recruitment and participation of this patient group in long-term quantitative studies still is difficult and the small sample size is similar to comparable previous studies [11;13].

The main strength of this study is the prospective design, despite the small patient numbers. Our sample seems representative for healthy BRCA1/2 mutation carriers, including the finding that breast cancer was detected in the mastectomy specimens of two women [9;14;16;50;51]. Furthermore, the prediction model of body image provided medium to large effect sizes for the risk factor preoperative cancer distress, providing a good prediction for a negative body image after BPM-IBR [35]. We, therefore, recommend further exploring preoperative cancer distress in these patients and to pay more attention to those who are highly distressed to help them adapt better to their new body image after surgery. Nonetheless, a larger sample should be included in the future to confirm our findings and to support our inferences.

It is of great importance to inform patients *and* their partners about positive as well as negative consequences of BPM-IBR so they can form realistic expectations. This may help them to anticipate untoward side-effects after surgery [10;13;21;52-55]. It is preferable for all professionals involved to be aware of and enquire about psychosexual adjustment problems during follow-up visits. Psychosocial professionals should be sufficiently knowledgeable about onco-genetics. Psychological support should be offered after BPM-IBR in an integrated approach as long as the option for BPM-IBR is provided, as a substantial proportion of women face ongoing psychosocial issues [11;56].

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