A Couples-Based Team Approach to

Prophylactic Bilateral Mastectomy and Social Disapproval

By

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ABSTRACT

Prophylactic bilateral mastectomy (PBM) is the current recommended course of action for women with increased genetic risk for breast and ovarian cancer. Nevertheless, many receive negative feedback from family and friends surrounding the decision to undergo this surgery because they do not have cancer when the decision is made; this results in a limited support network for coping with their PBM. Low social support is associated with depression, negativity, and anxiety. Women who had a PBM, were currently undergoing or had completed reconstruction, and were in a committed romantic relationship at the time of the surgery were surveyed (*N* = 53). The hypotheses that women who received negative feedback about their decision to have a PBM would have poorer individual well-being, and that the use of a couples-based team approach would moderate these adverse effects were tested. Data analyses support the hypotheses that women in couples taking a team approach to PBM have better individual well-being. The effects of negative feedback from others about the decision to undergo a PBM on personal mental health were moderated by use of a couples-based team approach. Women who received negative feedback from multiple sources had better outcomes if they used a couples-based team approach. Many women have a preventative oophorectomy around the same time as their PBM. Menopause is associated with side effects such as increased vasomotor symptoms and decreased sexual functioning. The hypothesis that surgical menopause is related to declines in sexual satisfaction following PBM was also tested. Regression analysis revealed no relationship. This study indicates that women who experience social disapproval and lack collaborative support from their significant other may be at increased risk for poor individual well-being following PBM.

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Introduction

HBOC Genetic Mutations

Hereditary breast and ovarian cancers (HBOC) are related to several genetic mutations that increase one's risk of breast and ovarian cancer. BRCA 1 and BRCA 2 mutation variants account for approximately 90% of HBOC genetic mutations (Ford et al., 1998), others include ATM, CHEK2, TP53, and BARD 1 (Caminsky, Mucaki, Perri, Lu, Knoll, & Rogan, 2016). These deleterious genetic mutations also increase the risk of cancer in other sites such as the stomach, skin, cervix, or prostate (Johannsson, Loman, Möller, Kristoffersson, Borg, & Olsson, 1999). Everyone has these genes, and numerous mutations or variants of each exist; however, not all are harmful, and some are even protective (Jabaley Leonarczyk & Mawn, 2015). Deleterious BRCA mutations confer up to 87% lifetime risk of developing breast cancer (Easton, Ford, & Bishop, 1995), and 28-66% lifetime risk of developing ovarian cancer (Risch et al., 2001). These percentages vary by the specific mutation inherited.

The general population has a breast cancer risk of approximately 12% (Howlander, 2017). With 1 in 8 women being diagnosed with breast cancer, it is likely that most people have a relative with breast cancer, or a family history of cancer. Although HBOC accounts for only about 5% to 10% of breast cancers and 25% of ovarian cancers (Caminsky et al., 2016), the high prevalence of non-hereditary cancer can cause a "family history" even without genetic mutation. Those with a strong family history of cancer, or who have an Ashkenazi Jewish ancestry coupled with ovarian cancer in the family, experience higher prevalence of HBOC mutations (Ford et al., 1998). Testing for genetic mutations can offer relief to recipients of negative results, while positive tests can indicate courses of action for behavioral or medical interventions (Cameron, Sherman, Marteau, & Brown, 2009). Responses to unfavorable genetic test results include surveillance, chemoprevention, and surgery, as described below.

Surveillance

It is recommended that BRCA mutation carriers undergo surveillance, or cancer screening, every six months beginning at age 25 (Warner et al., 2004). For breast cancer screening, a regimen of self-exams, clinical exams, and imaging (MRI, ultrasound, mammogram) is used (Stan, Shuster, Wick, Swanson, Pruthi, & Bakkum-Gamez, 2013). For ovarian cancer screening, pelvic exams, pelvic ultrasound, and serum CA-125, a blood test which measures levels of cancer antigen 125 in the blood stream, may be used. The surveillance route is noninvasive, but suspicious or ambiguous findings can lead to additional testing and emotional distress (Stan et al., 2013). This may lead women to turn to surgery after experiencing fatigue from repeated emotionally exhausting and costly screening (Hoskins & Greene, 2012).

Most women who choose surveillance are younger and without children. They often feel that they have time on their side and can select surgical options after reaching goals such as establishing their career or starting their family (Hesse-Beiber, 2014). Women may choose surveillance to delay surgery for goal planning (Hesse-Biber, 2014). These women may consider surgery not a matter of "if", but rather "when". This option may create the narrative of racing against time seen in several book and blog titles authored by mutation carriers (e.g., "*Ticking Time-Bombs;" "Dangerous Boobies: Breaking up with My Time-Bomb Breasts"*). There may also a sense of urgency to find a partner and have children prior to switching strategy to surgical options (Leonarczyk &

Mawn, 2015). Mastectomy removes the ability to breastfeed (Hoskins & Greene, 2012). For some women, breastfeeding is an important and emotional experience causing them to delay prophylactic bilateral mastectomy (PBM) until after weaning. Other women choose to have a PBM prior to pregnancy and forego breastfeeding. Most practitioners recommend removal of the ovaries and fallopian tubes, or prophylactic bilateral salpingo-oophorectomy, after patients complete their families to further reduce their risk of cancer.

Medicinal Interventions

Chemoprevention therapy is another option for BRCA mutation carriers. Tamoxifen, an estrogen receptor modulator used to treat estrogen-dependent cancers, can also be used as a means for prevention (Bonanni & Lazzeroni, 2013). For mutation carriers, chemoprevention is used during remission from cancer to prevent contralateral recurrence; its effectiveness in this role led to trials of chemoprevention for mutation carriers prior any cancer occurrence. One study found Tamoxifen reduced occurrence of invasive breast cancer by 49.5% (Fischer et al., 1998). Nevertheless, chemotherapy for prevention among mutation carriers is not commonly used and is quite controversial, with studies finding ratings of acceptability between 22.1% and 34% (Bonanni & Lazzeroni, 2013). Associated adverse effects related to chemoprevention therapy include uterine cancer, stroke, cataracts, and thromboembolic events (Stan et al., 2013). Therefore, tamoxifen is not recommended for those who have not had a hysterectomy or who have had previous deep vein thrombosis or pulmonary embolism (Kramer & Brown, 2004).

Oral contraceptives (OC) may reduce risk for ovarian cancer by up to 50% (Iodice et al., 2010). There is some controversy with the use of OC as means for ovarian cancer prevention, however, because some findings suggest increased risk of breast cancer

(Gadducci, Biglia, Cosio, Sismondi, & Genazzani, 2010). One possible explanation for this is that OC formulations from prior to 1975 had higher doses of hormones. A meta-analysis by Iodice and colleagues (2010) found that use of OC with the older formulation was related to increased risk, while use of the newer lower dose OCs is not.

Surgery

Prophylactic bilateral mastectomy. Women at increased risk for breast cancer may view PBM as an opportunity to gain control of their risk and avoid an "inevitable" cancer diagnosis (Hoskins & Greene, 2012). A PBM reduces the risk of getting breast cancer by 90% to 94% (Hartmann et al., 1999). Following the PBM, an HBOC mutation carrier will have less risk for breast cancer than the average risk of the general population.

There are several options with respect to breast reconstruction, with corresponding opportunities for complications to occur. Women may opt out of reconstruction altogether, choose a direct-to-implant procedure if they qualify, choose to reconstruct the breast by grafting tissue from another area, or choose to use expanders to create a space large enough to take an implant during a later surgery. During a skin-sparing mastectomy, the subcutaneous breast tissue is removed, and the skin is retained allowing for reconstruction to begin (Singletary, 1996). The nipple-areolar complex is also breast tissue, so it is usually removed as well. Some women opt for a nipple-sparing mastectomy which preserves the nipple-areolar complex while removing the rest of the breast tissue. Recent studies have found comparable risk reduction outcomes for skin-sparing and nipple-sparing mastectomy techniques (see Yao et al., 2015).

Quality of life after PBM. A review of quality of life following PBM done by Razdan, Patel, Jewell & McCarthy (2016) found the majority of patients reported favorable results for PBM outcomes for psychosocial well-being and body image. Sexual well-being outcomes had mostly favorable, but mixed results. It is noted however, that many of the analyses in these studies were done with ad hoc instruments making it difficult to compare results. The most negative effect was on somatosensory function, such that women often experience loss of sensation or have continued pain and discomfort in the breast area.

In contrast, Lodder et al. (2002) reported less favorable results. They investigated effects of genetic testing results by collecting data from a group of women at the time of receiving their results, and at 6 months and 12 months post-testing. Interestingly, they found that the group of women who had opted for mastectomy had lower body image and sexual relationship scores than both the group who tested negative and the group who tested positive but had opted for surveillance; scores were lower both at the time of receiving test results and after mastectomy. This finding of consistent lower body image scores beginning prior to PBM suggests that the surgery itself was not fully responsible for the low scores in this group. Women with positive test results may feel betrayed by their bodies resulting in poorer body image (BuzzFeed Video, 2017). Lodder noted that they did not use a validated scale to measure body image, so the extent of the problem may not be clear.

Gopie and colleagues (2013) also found some negative impact from PBM on body image. Women with high preoperative cancer distress scores experienced decreased body image at 6 months following PBM and at the post-reconstruction follow-up, 21 months after receiving test results on average. There were many women in this sample who had body image issues prior to their PBM that did not change following reconstruction. Gopie also used an ad hoc, study-specific body image scale in their analyses. Although overall partner relationship satisfaction did not change over time, there was a trend of decline for sexual relationship satisfaction. It is possible that this trend may be related to the co-ocurrence of risk-reducing prophylactic bilateral salpingo-oophorectomy (PBSO; see below).

Several studies, even those in which a majority of participants with favorable outcomes, uncovered similar factors leading to dissatisfaction (Lodder et al., 2002; Bresser et al., 2006). Surgical complications, changed appearance affecting femininity, changes in sexual activity, and unnatural-looking or -feeling results were contributing factors. In addition, women whose physicians strongly recommended PBM were worse off than those who came to the decision on their own (Gopie et al., 2013; Razdan et al., 2016). Other contributons to poorer adjustment were unmet expectations and lack of information (Bresser et al., 2006; Lodder et al., 2002). Overall, however, very few women across studies regretted their decision to have a PBM, and many studies reported no participant regret regarding their decision. The only participant with regret from Lodder's study (2002) cited the lack of information regarding psychosocial consequences and effects on physical well-being as the cause of her regret.

Prophylactic bilateral salpingo-oophorectomy. PBSO reduces the risk of ovarian cancer 80%–85% and breast cancer 50%–72% risk in BRCA carriers (Matloff, Barnett, & Bober, 2009). Many BRCA related breast cancers are estrogen sensitive and therefore removal of the ovaries reduces the risk of breast cancer. Removal of the ovaries results in immediate menopause which has been related to an increase in vasomotor symptoms and decrease in sexual functioning (Finch et al., 2011). Side effects can include vaginal dryness, decreased libido, and difficulty achieving orgasm (Matloff, Barnett, & Bober, 2009; Finch et al., 2011). Many women with HBOC mutations report not fully being informed of the impact this surgery may have. Similar to PBM, most women were satisfied with the decision to have their surgery regardless of any side effects (Finch et al., 2013). They felt that the risk reduction benefits out-weighed these other issues. No studies to our knowledge tested the potential influence of an accompanying risk-reducing PBSO on decline in sexual well-being or sexual relationship satisfaction associated with PBM.

Recent research has indicated that hereditary ovarian cancer may originate in the fallopian tubes or other epithelial tissue and may therefore be secondary ovarian cancer rather than primary (Kwon et al., 2013). Women may opt to remove their fallopian tubes upon completion of child-bearing and delay removal of the ovaries until closer to the time of natural menopause. This option reduces their risk and is less costly in terms of potential effects on quality of life.

A Different Kind of Decision-Making

As noted above, those who receive positive test results for a deleterious HBOC mutation may utilize surveillance, medicinal interventions, or surgical procedures to manage their risk. The decision-making for this group differs from typical cancer-related decision-making. Survival is often at the forefront of decisions made to treat existing cancer and may outweigh any potentially negative psychosocial outcomes. Patients are presented with statistical information about potential treatment options and effects on survival. In these situations, patients generally follow recommendations made by experienced healthcare professionals (Hesse-Biber, 2014).

In contrast, women who have received positive genetic test results for an HBOC-related mutation have not been diagnosed with cancer yet and have a more flexible decision-making timeline. Decisions are driven not only by the statistical risk of developing cancer, but more prominently by a host of social factors, namely familial history, death of a close relative, and social or information support from a network of friends, family, and online groups (Hesse-Beiber, 2014). For example, death of a close relative as a result of cancer, especially a mother, predicts a woman's selection of surgical options (Wenzel et al., 2012; Hesse-Beiber, 2014; Samama, Hasson-Ohayon, Perry, Morag, & Goldzweig, 2014). Women whose mothers battled cancer, but did not die, also preferred preventative surgery over a surveillance route (Hesse-Beiber, 2014). The question becomes, do you want to treat a disease you don't have and might not even get?

Social Disapproval of PBM

There is controversy surrounding the decision to undergo PBM because women are not afflicted by cancer when the decision is made. Many women receive negative feedback from early confidants and ultimately decide not to inform or discuss with others, resulting in a limited support network (Lloyd et al., 2000). Friend or family disapproval of PBM discourages communication, which increases isolation. Family communication is important, as it has been linked to improved long-term adjustment and reduced breast cancer-specific and general distress (den Heijer et al., 2011; Lloyd et al., 2000). A study by den Heijer and colleagues (2011) found that open family communication about hereditary cancer risk was directly related to lower psychological distress and this effect was not mediated by social support. This demonstrates the importance of open communication within the family, which offers benefits regardless of other social support. Increasing family member understanding and willingness to discuss the implications of genetic risk and benefits of preventative options is a potential arena for future research or intervention.

Impacts on Partners and Relationships

There has not been much research on relationship adjustment for at-risk women undergoing PBM, although multiple studies suggest the effects of PBM on relationships should not be underestimated (Gopie et al., 2013). Any negative aspects felt at a personal level could affect the relationship as well. Depression, negativity, and anxiety that may be related to genetic test results and PBM are all widely known to be negatively correlated to marital functioning (Watts, Sherman, Mireskandari, Meiser, Taylor, & Tucker, 2011). Additionally, low self-esteem and body image combined with poor communication can have a profound negative impact on marriage (Rowland & Metcalfe, 2014). There is, however, more research on couples' experiences with receiving genetic results indicating increased risk, and on couples' or partner's experience with mastectomy for existing cancer.

PBM studies. A qualitative study by Lloyd et al. (2000) found that women's greatest support came from their spouse. The spouse felt increased stress during the mastectomy and reconstruction in response to balancing work, taking care of the children, and supporting their wife. The initial surgery has about a 6-week recovery period, which not only imposes physical restrictions on the patient, but requires assistance from the partner with self-care and housework, and likely requires a significant amount of time out of work leading to financial strain. The quality of the relationship prior to the PBM was related to the type of impact afterward. Couples with lower ratings of their relationship quality felt a negative impact, while those with higher ratings felt a positive impact.

The study by Lodder et al. (2002) discussed previously also interviewed the partners of the women who had PBM. The decreases in intimacy seen were likely due to the women, rather than their partners, feeling inhibited. As with the Lloyd study, if there were pre-existing communications problems, they were compounded with the additional strain of the surgery and recovery.

Genetic testing. A study looking at male partners of women who receive positive genetic testing results related to HBOC found they experience similar psychological concerns and distress as the women themselves (Mireskandari et al., 2006). Distress may be caused by suppressed communication, feeling the need to provide emotional support, and worries about future children inheriting the mutation (Metcalfe, Liede, Trinkaus, Hanna, & Narod, 2002). Another source of distress stems from the fear that their wife may develop or die of cancer; this can lead to changing future goals about careers or families in response to testing positive (Metcalfe et al., 2002). Challenges related to coping with increased risk of cancer may place strain on a couple's relationship (Watts et al., 2011). Partners are often caught between providing support and managing their own distress (Sherman, Kasparian, & Miraskandari, 2009). Low levels of communication and partner support have been associated with higher distress at the time of genetic testing, 6 months after, and up to 2 years after receiving positive genetic results. (Van Oostrom et al., 2007; Wylie, Smith, & Botkin, 2003).

A 2016 qualitative study by Mauer, Spencer, Dungan, and Hurley that addressed changes within the relationship following genetic testing found that about 20% became less intimate, but 40% discussed the future more frequently. For those who had not yet had a PBM, there was high concern for their partner's health or lifespan. There were also concerns about how having a PBM could affect their sexual relationship, and for the potential loss of breast sensation or attractiveness.

Mastectomy for existing cancer. Many studies examining the effects of mastectomy on relationships or spouses have been done in the context of existing cancer. A review by Rowland and Metcalfe (2014) summarized the literature on male partners' experiences of their wives' breast cancer. Spouses were stressed by diagnoses, particularly anxious during decision making, felt death anxiety, and were bothered by partner's distress or pain. A majority of men felt a negative impact on their sexual relationship, while others did not perceive this impact, were supportive, and encouraged positive body image in their partners. Some men were active in the decision-making process while others were removed, possibly as a defense mechanism, leading to closed communication. Some topics that were difficult to discuss include changes in intimacy and feelings about their wives' altered body, because they felt this made them appear insensitive.

Importance of Dyadic Communication

Closed communication is associated with adverse outcomes for couples across studies exploring potential effects of mastectomy, genetic testing, and PBM. As mentioned previously, open communication is key to long-term individual adjustment.

Communication is also an essential facet of dyadic adjustment. Information from healthcare providers is usually directed at the patient, leaving partners feeling marginalized and wanting more information (Rowland & Metcalfe, 2014). They often reported that asking questions, specifically about physical alteration of the body or how to prepare to see surgical results, made them appear insensitive. Some male partners discussed their feelings with close family or friends, while others did not because they felt their concerns would appear superficial, resulting in backlash rather than support. These negative experiences discourage communication and could lead to suppression. Likewise, emotional suppression negatively impacts the relationship resulting in less feelings of acceptance causing distancing to occur (Cameron & Overall, 2017). Partners should be encouraged to have open communication, feel comfortable expressing concerns, and navigate the decision-making process together.

Team Approach

A recent study by Ahmad, Fergus, Shatokhina, and Gardner (2017) found that couple identity, or “we-ness,” increased a woman’s confidence in her ability to cope with cancer treatment and related stressors, thus improving individual adjustment. In communal coping, a stressor is a “we-event” in which both members of the relationship share responsibility for addressing the stressor through open communication and collaboration (Lyons, Mickelson, Sullivan, & Coyne, 1998). Similarly, a team approach as defined by Watts et al. (2011) is “the extent to which each member of the couple perceived himself or herself to adopt a collaborative approach to coping with the woman’s cancer risk, including engaging in open communication.” The “we-event” leads couples to feel that they are "in it together" which enhances relationship satisfaction

(Watts et al., 2011). This allows the couple to express concerns and compassion, attenuate stress, and share the load of a disease or illness. Individual psychological adjustment improved for patients with chronic illness who perceived their partner to be involved through collaborations and support (Berg & Upchurch, 2007).

A recent theoretical outline of thriving through relationships has postulated that collaborative action taken by a couple not only buffers stress but enhances individual and relationship outcomes (Feeney & Collins, 2015). To promote thriving, a partner provides encouragement or motivation, uses open communication, helps the individual frame a challenge as an opportunity for growth, assists with planning or set-backs, and encourages the individual to take action. This perspective takes team approach a step further, suggesting that gains can be made beyond simply maintaining levels of individual well-being or relationship satisfaction during a challenging time. This is consistent with other findings that for some couples, cancer strengthened their relationships with the spouse being caring and supportive, especially in couples who had been together longer (Rowland & Metcalfe, 2014).

Hypotheses

The present study explored the effects of a couples-based team approach to PBM on individual well-being. The first hypothesis was that women who experience social disapproval of their PBM would have poorer outcomes. Second, those with partners who take a team approach to their PBM will have greater individual well-being. Third, we hypothesized the interaction between negative feedback and team approach would still be present when controlling for marital duration, surgical complications, and SES. We also investigated whether the association of PBM with lowered sexual satisfaction was influenced by the occurrence of prophylactic bilateral oophorectomy.

Methods

An online survey through Qualtrics was posted in various Facebook support groups. Women over 18 with a genetic mutation related to hereditary breast cancer, had a prophylactic bilateral mastectomy with or without breast reconstruction, and were in a committed romantic relationship at the time of the mastectomy were recruited. Although 84 participants began the survey, there was a high attrition rate; only 62% completed all measures, leaving 53 participants.

Participants

Basic demographic information was collected along with information related to the surgery such as dates, number of surgeries, number of complications, reconstruction status, and type of HBOC mutation (see Table 1). This was a relatively homogeneous sample of primarily Caucasian (97%), North American women (86.8%), who were highly educated (59.8% with a 4-year degree or higher), and had a household income greater than $100,000 (64.2%). With respect to breast reconstruction, 51% had completed reconstruction, 32% were currently undergoing reconstruction, and 11% had opted out of reconstruction. Women ranged in ages from 25 to 64 years. The average relationship duration was 13.8 years, with only 7.5% of women having a relationship duration of less than 5 years. Only one participant was no longer in the same relationship as at the time of her PBM, although that relationship lasted 11 years. With respect to the mutations carried, 48% were BRCA 1, 48% were BRCA 2, and the remaining 4% were PALB2, CHEK2, or VUS.

Table 1

Demographics.

Participant Characteristics	Frequency	Percent
Age		
25 – 34	11	20.8
35 – 44	25	47.2
45 – 54	11	20.8
55 – 64	5	9.4
Missing	1	1.9
Household Income		
Less than $20,000	2	3.8
$20,000 - $59,999	7	13.2
$60,000 - $99,999	10	18.9
$100,000 - $139,999	18	34.0
More than $140,000	16	30.2
Education		
Less than high school degree	2	3.8
High school graduate (or GED)	1	1.9
Some college but no degree	5	9.4
Associate degree or Trade	9	17.0
Bachelor's degree	15	28.3
Graduate or Professional degree	21	39.7
Relationship Duration		
3 - 5 years	4	7.5
6 - 10 years	15	28.3
11 - 15 years	12	22.6
16 - 20 years	5	6.1
20 - 25 years	7	13.2
More than 25 years	7	13.2
Missing	3	5.7
Reconstruction Status		
Completed reconstruction	27	50.9
Currently undergoing reconstruction	17	32.1
No reconstruction	6	11.3
Missing	3	5.7
Number of Complications		
0	18	34.0
1	19	35.8
2	6	11.3
3	5	9.4
4	4	7.5
More than 5	1	1.9

Bilateral Oopherectomy		
No	27	50.9
Yes	26	49.1

Instruments

Sources of negative social feedback. Participants were asked "*Did you receive negative feedback from friends, family, acquaintances about your decision to have your prophylactic bilateral mastectomy (PBM)? If yes, please check all of the following that apply*." Relationships listed were partner, immediate family, extended family, partner's immediate family, partner's extended family, close friends, other friends or acquaintances, and co-workers.

Individual well-being. As indicators of individual well-being, we assessed mental health through the Depression, Anxiety, and Stress 21 item Scale (DASS21), rumination, and self-image through the Body Image Scale (BIS) and BREAST-Q. The DASS21 (Lovibond & Lovibond, 1995) has three subscales measuring depression, anxiety, and stress by a 4-point Likert scale ranging from 0 (*Did not apply to me at all*) to 3 (*Applied to me very much, or most of the time*); Cronbach's α = .95. Item example: "I couldn't seem to experience any positive feeling at all."

The Rumination scale (Nolen-Hoeksema, 2000) asks about the frequency of rumination on a Likert scale ranging from 1 (*almost never*) to 4 (*almost always*). The items ask what a person "*generally*" does when "*they feel down sad or depressed*", such as how often they think "*Why can't I handle things better*?" Scores can range from 22 to 88, with an average score of 42 for women (Nolen-Hoeksema, Larson, & Grayson, 1999); Cronbach's α = .96.

The BIS (Fingeret, Vidrine, Arduino, & Gritz, 2007) has 8 items rated on a 4-point scale of 0 (*not at all*) to 3 (*very much*). A sample item is, "*Have you been feeling less sexually attractive as a result of your disease or treatment*?"; Cronbach's α = .93.

The BREAST-Q (Pusic et al., 2009) is a validated scale addressing quality of life and patient satisfaction following mastectomy and with a version for reconstruction and another for no reconstruction. We used the Satisfaction with Breasts (Cronbach's α = .93), Psychosocial Well-Being (Cronbach's α = .95), Sexual Well-Being (Cronbach's α = .94), and Physical Well-Being Cronbach's α = .91) subscales.

Team approach. Literature on team approach or communal coping uses a two-item scale with one item assessing open communication and the other assessing cooperative action, or dyadic coping (e.g., Watts et al., 2011; Biehle & Mickelson, 2011). To more thoroughly investigate these individual items, we selected validated scales related to each. We also included 3 survey-specific items on a sliding scale to assess "we-ness" as a means of measuring communal coping as described below.

To assess open communication, we included the Cancer-Related Communication Problems scale (CRCP; Kornblith et al., 2006). This is a 15 item, 5-point Likert scale ranging from 1 (*very rarely*) to 5 (*very often*). Modifications were made to apply to cancer prevention. Examples of modifications include adding the word "prevention" into items, such as *"I talk over with my spouse about how cancer [**prevention**] treatment has changed my body (e.g., removal of breast, uterus, or ovaries),"* or changing items to future tense such as from "having cancer" to "getting cancer"*I don't tell my spouse how scared I am about [**getting**] cancer."* Cronbach's α = .80 with the modifications.

For cooperative action, we used the Dyadic Coping Inventory (DCI; Bodenmann, 2008) and three survey-specific questions. The DCI is a 37-item, 3-point Likert scale anchored with 1 (*not true),* 2 *(sometimes true),* and 3 *(often true),* and includes items such as *"We engage in a serious discussion about the problem and think through what has to be done."* Cronbach's α = .94.

We also created 3 new items to assess "We-ness" by positioning "we" statements juxtaposed to "I' statements. We used a sliding scale ranging from partner not participating at all (*"I"* statements) to fully participating in treatment and planning (*"We" statements*). Scoring was done on a 1-10 sliding scale with the numeric values hidden from participants. The items were: *"I attended all of my doctor appointments on my own"* as opposed to "*We attended all of the doctor appointments together*," *"I made all decisions about my treatment on my own"* as opposed to *"*We made all decisions about treatment as a team," and *"I am getting through this on my own"* as opposed to *"We are getting through this together."* Cronbach's alpha for these items was only .64, so they were not included in the team approach composite score.

Sexual satisfaction. The Sexual Satisfaction Scale for Women **(**SSS-W; Meston & Trapnell, 2005) is a 30-item, 5-point Likert scale scored from 1 (*strongly disagree*) to 5 (*strongly agree*) that touches on 5 domains examining Contentment, Communication, Compatibility, Personal Concern, and Relational Concern. Items were summed, allowing for scores from 30-150. Cronbach's α = .96.

Data Reduction and Analysis

Missing data. Inspection of the data revealed that the most common pattern of missingness was likely due to attrition. There was progressively more missing data throughout the survey scale by scale. The number of women who completed each scale, in the order they were presented, are shown in Table 2. Within the cases not affected by attrition, missing data values were less than 5% per scale. All scales were scored by computing an average of the items for the scale.

Table 2

Scale Completion and Missing Data Percentages

Scales	*N*	Missing
Depression, Anxiety, & Stress Scale 21	68	< 1 %
Rumination Scale	66	< 1 %
Body Image Scale	65	-
Breast-Q Subscales	59	4 %
Dyadic Coping Inventory	56	< 1 %
Cancer-Related Communication Problems	53	< 1 %
Sexual Satisfaction Scale	50	< 1 %

Scale scoring and creation of composite indicators. For the DASS21, BIS, and Rumination Scale, item responses were averaged. An average was taken of the standardized scores for the Breast-Q Satisfaction with Breast, Psychosocial Well-Being, Sexual Well-Being, and Physical Well-Being subscales after scoring using the QScore software. A composite variable was made by summing the average Breast-Q subscale standardized scores and reversed standardized scores of the BIS, DASS21, and Rumination Scale so that higher scores indicated higher individual well-being. The scales scores included in the composite indicator for individual well-being were all correlated at $p < .01$. See Table 3 for the correlation matrix.

For the DCI and CRCP, item responses were averaged. The standardized score for DCI and the reversed standardized score for CRCP were summed to create a composite indicator for team approach. Higher values signal a stronger team approach. We chose not to include the survey-specific team approach questions, which had low correlations in our sample. See Table 3 for correlation matrix.

Table 3

Pearson Correlations among Study Variables

	DASS21	Rumination	Breast-Q	CRCP	DCI
Body Image	$.42^{***}$	$.34^{**}$	$-.78^{**}$	.20	.06
DASS21		$.68^{***}$	$-.48^{***}$	$.28^{*}$	-.23
Rumination			$-.42^{***}$	.27	-.10
Breast-Q Subscale Composite				$-.38^{***}$	.07
Cancer-Related Comm. Prob.					$-.69^{***}$

* *p* < .05. ** *p* < .01. *** *p* < .001.

Note. Correlations of variables composing Individual Well-Being are highlighted in light gray. Correlations of variables composing Team Approach are highlighted in dark gray.

For Breast-Q subscale composite and Dyadic Coping Inventory, higher scores indicate higher well-being. For all other scales, lower scores indicate higher well-being.

Results

Negative feedback sources

Approximately 60% of the sample received negative feedback from one or more sources. The most common sources of negative feedback were other friends or acquaintances (25%), extended family (23%), immediate family (17%), and close friends (15%).

Table 4

Sources of Negative Feedback

Negative feedback	Frequency	Percent
Number of sources		
0	21	39.6
1	17	32.1
2	12	22.6
3	1	1.9
4	1	1.9
5	1	1.9
Source relationship		
Partner	3	5.7
Immediate family	9	17.0
Extended family	12	22.6
Partner's immediate family	3	5.7
Partner's extended family	2	3.8
Close friends	8	15.1
Other friends/ acquaintances	13	24.5
Co-workers	4	7.5

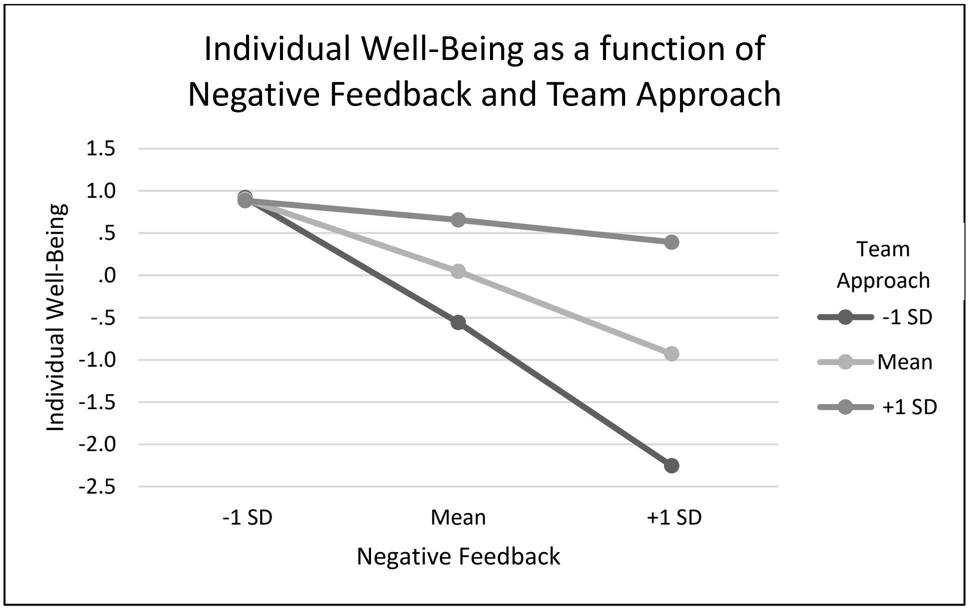
Social Disapproval and Team Approach

To investigate our first hypothesis, that women who experience social disapproval of their PBM would have poorer outcomes, and our second hypothesis, that the relationship between negative feedback about the decision to undergo PBM and individual well-being would vary as a function of team approach, negative feedback (mean-centered), team approach (mean-centered), and an interaction term calculated from these variables were entered as predictors of individual well-being using the PROCESS macro (see Hayes, 2013). Conditional main effects for negative feedback emerged, such that women who received negative feedback from more sources had poorer individual well-being, b = -.84, SE = .33, t(53) = -2.51, p = .02. These effects were qualified by a significant negative feedback and team approach interaction, b = .33, SE = .16, t(53) =

2.08, $p = .04$, $\Delta R^2 = .07$. Simple slopes analyses revealed that for women with relatively low (1 SD below the mean) and moderate (mean) levels of team approach, negative feedback significantly predicted poorer individual well-being, $b = -1.46$, $SE = .49$, $t(53) = -2.98$, $p < .01$, and $b = -.84$, $SE = .33$, $t(53) = -2.51$, $p = .02$, respectively. At high levels of team approach use (1 SD above the mean), negative feedback was uncorrelated with individual well-being, $b = -.22$, $SE = .40$, $t(53) = -.56$, $p = .57$.

Figure 1

Relationship between Negative Feedback and Individual Well-Being Varies as a Function of Team Approach



Covariates. To test our third hypothesis, we controlled for marital duration, surgical complications, and SES (education or income). Each variable was entered as a covariate in the model one at a time. No covariates were significantly related to individual well-being. To investigate the occurrence of statistical suppression, we examined changes in the interaction coefficients after covariates were added, as follows:

for number of complications, change in interaction coefficient = .01; for education, change in interaction coefficient = -.02; for income, change in interaction coefficient = .01; and for relationship duration, change in interaction coefficient = -.02. The interaction terms did not change by much (+/- .02) for any covariate, therefore, there is no indication of statistical suppression.

Sexual Satisfaction

To investigate our research question, about a relationship existing between sexual outcome and coinciding oophorectomy, a regression analysis was performed. Oophorectomy, or surgical menopause, was not significantly related to sexual satisfaction, $b = 1.82$, $SE = 5.91$, $t(53) = .31$, $p = .76$. Scores for the SSS-W ranged from 42 to 147 with a mean of 104.45 and standard deviation of 25.60.

Discussion

Social Disapproval

Women who experienced social disapproval about their decision to have a PBM reported poorer individual well-being. These results are consistent with prior findings that negative social feedback about health care decisions can adversely impact individual well-being (Lloyd et al., 2000). Lloyd found that women received very “polarized” responses from those they decided to tell about their decision to have the PBM. Because negative opinions were so strong, the participants became selective in who else they told. This response has the potential to further limit a woman’s social support network.

Team Approach

Women with low levels of perceived team approach were more affected by negative feedback. Lack of support from one’s partner may compound the adverse effects of social disapproval from other sources. Even at moderate levels of team approach, more social disapproval was also associated with increased adverse effects on individual well-being, indicating that an average level of team approach does not fully attenuate the negative impact of stressors.

On the other hand, for women who reported a stronger team approach, negative feedback from others was not related to their individual well-being. This is consistent with previous research indicating that team approach buffers adverse effects of stressors (Ahmad et al., 2017; Berg & Upchurch, 2007; Lyons et al., 1998). This finding exemplifies the strong buffering effect offered by a couples-based team approach. When a woman has her partner’s collaborative support, negative feedback from others does not affect her individual well-being. The dyadic coping and open communication comprising team approach allows the couple to express concerns and compassion, attenuate stress, and share the load of a disease or illness (Lyons et al., 1998). Having a partner in their corner to actively support and encourage their decisions likewise buffers against added stress from social disapproval. Ahmad (2017) found that partner support increases confidence in women’s ability to cope.

Conversely, a study by M. den Heijer (2011) did not find a relationship between support offered by a significant other and individual well-being. Their model also included support from family and support from friends, both related to improved outcomes, which may overlap with support from a significant other. The authors acknowledged that this lack of relationship may have resulted from unclear instructions as to who to consider as a significant other. If the directions explicitly directed participants to think of a romantic significant other, the results may be in line with our findings of support from a romantic close other. They did, however, find that open communication about hereditary risk also allows for opportunity for close others to help reframe cancer worries. Those women who feel supported by their close others are more likely to engage in open communication, possibly leading to improved individual well-being (M. den Heijer et al., 2011).

Surgical Menopause and Sexual Satisfaction

Poorer sexual satisfaction was not related to oophorectomy. Previous research indicated mixed results regarding sexual well-being following PBM but failed to address coincidence of prophylactic oophorectomy. This study found no evidence that surgical menopause may be partially responsible for any decline in sexual satisfaction. A limitation, however, is that we did not ask if women who had an oophorectomy take hormone replacement therapy (HRT). HRT may mitigate adverse effects associated with menopause symptoms.

Future Directions and Limitations

One limitation of this study is that the measure of negative feedback women received about their decision may underestimate the number of sources. For example, a woman who checked that she received negative feedback from her immediate family may experience disapproval from both parents and multiple siblings, or simply from only one individual. The score for each of these women would be same for the present study. Given that negative feedback has been related to future selective disclosure (Lloyd et al., 2000), it may be fruitful to investigate who women disclose to, the order in which they do, and whether negative feedback from close family and friends influences their decisions to have the surgery. Additionally, it would be interesting to ask about how much they value each individual's opinion on the matter.

The high levels of education and household income within our sample raise a few questions. First, does this indicate that highly educated women are more familiar with information about PBM for risk management or have more access to it? Second, do women with higher incomes have access to better health care or more paid time off work, which in turn affords them the opportunity to have a PBM? Both questions may have grim implications. Women with lower SES may have less opportunity for prevention options. Hopefully, this is not the case, but rather an artifact of sampling error. Further research should investigate the incidence of PBM among women with a lower SES.

Conclusion

This is the first study to our knowledge that tests the effects of social disapproval about a medical decision on individual well-being. Women experiencing negative feedback about their decision who also lack the cooperative support of a partner may at be increased risk for poor individual well-being outcomes following PBM. Further exploration should investigate sources of collaborative support for single women. This is also the first study we know of that tests oophorectomy as a contributor to declines in sexual satisfaction outcomes typically associated with PBM.

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APPENDIX A

DEPRESSION, ANXIETY, & STRESS SCALE 21

DASS21 *Name:* *Date:*

Please read each statement and circle a number 0, 1, 2 or 3 that indicates how much the statement applied to you *over the past week*. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree, or a good part of time
3 Applied to me very much, or most of the time

1	I found it hard to wind down	0	1	2	3
2	I was aware of dryness of my mouth	0	1	2	3
3	I couldn't seem to experience any positive feeling at all	0	1	2	3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5	I found it difficult to work up the initiative to do things	0	1	2	3
6	I tended to over-react to situations	0	1	2	3
7	I experienced trembling (eg, in the hands)	0	1	2	3
8	I felt that I was using a lot of nervous energy	0	1	2	3
9	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10	I felt that I had nothing to look forward to	0	1	2	3
11	I found myself getting agitated	0	1	2	3
12	I found it difficult to relax	0	1	2	3
13	I felt down-hearted and blue	0	1	2	3
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15	I felt I was close to panic	0	1	2	3
16	I was unable to become enthusiastic about anything	0	1	2	3
17	I felt I wasn't worth much as a person	0	1	2	3
18	I felt that I was rather touchy	0	1	2	3
19	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3
20	I felt scared without any good reason	0	1	2	3
21	I felt that life was meaningless	0	1	2	3

APPENDIX B

RUMINATION SCALE

Ruminations_Scale

People think and do many different things when they feel depressed. Please read each of the items below and indicate whether you almost never, sometimes, often, or almost always think or do each one when you feel down, sad, or depressed. Please indicate what you generally do, not what you think you should do.

1 - almost never; 2 - sometimes; 3 - often; 4 - almost always

How often do you…

- Think about how alone you feel
- Think “I won’t be able to do my job if I don’t snap out of this”
- Think about your feelings of fatigue and achiness
- Think about how hard it is to concentrate
- Think “What am I doing to deserve this?”
- Think about how passive and unmotivated you feel.
- Analyze recent events to try to understand why you are depressed
- Think about how you don’t seem to feel anything anymore
- Think “Why can’t I get going?”
- Think “Why do I always react this way?”
- Go away by yourself and think about why you feel this way
- Write down what you are thinking about and analyze it
- Think about a recent situation, wishing it had gone better
- Think “I won’t be able to concentrate if I keep feeling this way.”
- Think “Why do I have problems other people don’t have?”
- Think “Why can’t I handle things better?”
- Think about how sad you feel.
- Think about all your shortcomings, failings, faults, mistakes
- Think about how you don’t feel up to doing anything
- Analyze your personality to try to understand why you are depressed
- Go someplace alone to think about your feelings
- Think about how angry you are with yourself

APPENDIX C

BODY IMAGE SCALE

Body Image Scale

Please indicate how often the following occur:

	Not at all; Sometimes; Often; Very often
Have you been feeling self-conscious about your appearance?	
Have you felt less physically attractive as a result of your treatment?	
Have you felt dissatisfied with your appearance when dressed?	
Have you been feeling less feminine as a result of your treatment?	
Did you find it difficult to look at yourself naked?	
Have you been feeling less sexually attractive as a result of your treatment?	
Did you avoid people because of the way you felt about your appearance?	
Have you felt dissatisfied about your body?	

APPENDIX D

BREAST-Q – SELECT SUBSCALES

Breast-Q

Response Options:
None of the time; A little of the time; Some of the time; Most of the time; All of the time

Satisfaction with Breasts Subscale

With your breasts in mind, in the past 2 weeks, how satisfied or dissatisfied have you been with:

- How you look in the mirror clothed?
- The shape of your reconstructed breast(s) when you are wearing a bra?
- How normal you feel in your clothes?
- The size of your reconstructed breast(s)?
- Being able to wear clothing that is more fitted?
- How your breasts are lined up in relation to each other?
- How comfortably your bras fit?
- The softness of your reconstructed breast(s)?
- How equal in size your breasts are to each other?
- How natural your reconstructed breast(s) looks?
- How naturally your reconstructed breast(s) sits/hangs?
- How your reconstructed breast(s) feels to touch?
- How much your reconstructed breast(s) feels like a natural part of your body?
- How closely matched your breasts are to each other?
- How your reconstructed breast(s) look now compared to before you had any breast surgery?
- How you look in the mirror unclothed?

Breast-Q Psychosocial Well-Being Subscale

With your breasts in mind, in the past 2 weeks, how often have you felt:

- Confident in a social setting?
- Emotionally able to do the things that you want to do?
- Emotionally healthy?
- Of equal worth to other women?
- Self-confident?
- Feminine in your clothes?
- Accepting of your body?
- Normal?
- Like other women?
- Attractive?

Breast-Q Sexual Well-Being Subscale

Thinking of your sexuality, since your breast reconstruction, how often do you generally feel:

- Sexually attractive in your clothes?
- Comfortable/at ease during sexual activity?
- Confident sexually?
- Satisfied with your sex-life?
- Confident sexually about how your breast(s) look when unclothed?
- Sexually attractive when unclothed

Breast-Q Physical Well-Being Subscale

In the past 2 weeks, how often have you experienced: - Neck pain?

- Upper back pain?
- Shoulder pain?
- Arm pain?
- Rib pain?
- Pain in the muscles of your chest?
- Difficulty lifting or moving your arms?
- Difficulty sleeping because of discomfort in your breast area?
- Tightness in your breast area?
- Pulling in your breast area?
- Nagging feeling in your breast area?
- Tenderness in your breast area?
- Sharp pains in your breast area?
- Shooting pains in your breast area?
- Aching feeling in your breast area?
- Throbbing feeling in your breast area?

APPENDIX E

DYADIC COPING INVENTORY

Dyadic Coping Inventory

This scale is designed to measure how you and your partner cope with stress. Please indicate the first response that you feel is appropriate. Please be as honest as possible. Please respond to any item by marking the appropriate case, which is fitting to your personal situation. There are no false answers.

Responses: very rarely; rarely; sometimes; often; very often

This section is about how you communicate your stress to your partner.
1. I let my partner know that I appreciate his/her practical support, advice, or help.
2. I ask my partner to do things for me when I have too much to do.
3. I show my partner through my behavior when I am not doing well or when I have problems.
4. I tell my partner openly how I feel and that I would appreciate his/her support.

This section is about what your partner does when you are feeling stressed.
5. My partner shows empathy and understanding to me.
6. My partner expresses that he/she is on my side.
7. My partner blames me for not coping well enough with stress.
8. My partner helps me to see stressful situations in a different light.
9. My partner listens to me and gives me the opportunity to communicate what really bothers me.
10. My partner does not take my stress seriously.
11. My partner provides support but does so unwillingly and unmotivated.
12. My partner takes on things that I normally do in order to help me out.
13. My partner helps me analyze the situation so that I can better face the problem.
14. When I am too busy, my partner helps me out.
15. When I am stressed, my partner tends to withdraw.

This section is about how your partner communicates when he/she is feeling stressed.
16. My partner lets me know that he/she appreciates my practical support, advice, or help.
17. My partner asks me to do things for him/her when he has too much to do.
18. My partner shows me through his/her behavior that he/she is not doing well or when he/she has problems.
19. My partner tells me openly how he/she feels and that he/she would appreciate my support.

This section is about what you do when your partner makes know his/her stress.
20. I show empathy and understanding to my partner.
21. I express to my partner that I am on his/her side.
22. I blame my partner for not coping well enough with stress.
23. I tell my partner that his/her stress is not that bad and help him/her to see the situation in a different light.
24. I listen to my partner and give him/her space and time to communicate what really bothers him/her.
25. I do not take my partner’s stress seriously.
26. When my partner is stressed I tend to withdraw.

27. I provide support, but do it so unwillingly and unmotivated because I think that he/she should cope with his/her problems on his/her own.
28. I take on things that my partner would normally do in order to help him/her out.
29. I try to analyze the situation together with my partner in an objective manner and help him/her to understand and change the problem.
30. When my partner feels he/she has too much to do, I help him/her out.

This section is about what you and your partner do when you are both feeling stressed.
31. We try to cope with the problem together and search for ascertained solutions.
32. We engage in a serious discussion about the problem and think through what has to be done.
33. We help one another to put the problem in perspective and see it in a new light.
34. We help each other relax with such things like massage, taking a bath together, or listening to music together.
35. We are affectionate to each other, make love and try that way to cope with stress.

This section is about how you evaluate your coping as a couple.
36. I am satisfied with the support I receive from my partner and the way we deal with stress together.
37. I am satisfied with the support I receive from my partner and I find as a couple, the way we deal with stress together is effective.

APPENDIX F

CANCER-RELATED COMMUNICATION PROBLEMS

Cancer Related Communication Problems

Please rate the following questions about cancer related partner communication as *Not true, Sometimes true,* or *Often true.*

My partner understands what it was like for me to undergo treatment to prevent cancer.

I don’t talk about my genetic predisposition problems with my partner because he/she gets upset when I do.

My partner doesn’t ask how my genetic predisposition affected my life.

I can’t talk about cancer with my partner because I get too upset.

I never know when my partner wants to talk about my risk for getting cancer and when he/she does not.

I talk over with my partner about how cancer prevention treatment has changed my body (e.g. removal of breast, ovaries, or uterus).

I confide in my friends more than my partner about my cancer prevention experience.

I talk with my partner about what to do if I am diagnosed with cancer.

When it comes to cancer, I only tell my partner what he/she wants to hear.

I don’t talk with my partner about how cancer prevention affects me sexually.

APPENDIX G

SEXUAL SATISFACTION SCALE FOR WOMEN

Sexual Satisfaction Scale for Women

Question Response Options:

Strongly disagree; Disagree; Neutral; Agree; Strongly agree

I feel content with the way my present sex life is.

I often feel something is missing from my present sex life.

I often feel I don't have enough emotional closeness in my sex life

I feel content with how often I presently have sexual intimacy (kissing, intercourse, etc.) in my life.

I don't have any important problems or concerns about sex (arousal, orgasm, frequency, compatibility, communication, etc.).

Question Response Options:

Completely satisfactory; Very satisfactory; Reasonably satisfactory; Not very satisfactory; Not at all satisfactory

Overall, how satisfactory or unsatisfactory is your present sex life?

Question Response Options:

Strongly disagree; Disagree; Neutral; Agree; Strongly agree

My partner often gets defensive when I try discussing sex.

My partner and I do not discuss sex openly enough with each other, or do not discuss sex often enough.

I usually feel completely comfortable discussing sex whenever my partner wants to

My partner usually feels completely comfortable discussing sex whenever I want to.

I have no difficulty talking about my deepest feelings and emotions when my partner wants me to.

My partner has no difficulty talking about their deepest feelings and emotions when I want him to.

I often feel my partner isn't sensitive or aware enough about my sexual likes and desires.

I often feel that my partner and I are not sexually compatible enough.

I often feel that my partner's beliefs and attitudes about sex are too different from mine.

I sometimes think my partner and I are mismatched in needs and desires concerning sexual intimacy.

I sometimes feel that my partner and I might not be physically attracted to each other enough.

I sometimes think my partner and I are mismatched in our sexual styles and preferences.

I'm worried that my partner will become frustrated with my sexual difficulties.

I'm worried that my sexual difficulties will adversely affect my relationship.

I'm worried that my partner may have an affair because of my sexual difficulties.

I'm worried that my partner is sexually unfulfilled.

I'm worried that my partner views me as less of a woman because of my sexual difficulties.

I feel like I've disappointed my partner by having sexual difficulties.

My sexual difficulties are frustrating to me.

My sexual difficulties make me feel sexually unfulfilled.

I'm worried that my sexual difficulties might cause me to seek sexual fulfillment outside my relationship.

I'm so distressed about my sexual difficulties that it affects the way I feel about myself.

I'm so distressed about my sexual difficulties that it affects my own well-being

My sexual difficulties annoy and anger me.
