EVALUATION OF AN INTERNET-BASED, PSYCHOSEXUAL INTERVENTION FOR COUPLES FOLLOWING TREATMENT FOR BREAST CANCER: A PHASE I TRIAL

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Abstract

Despite the well-established evidence that many breast cancer survivors encounter some degree of difficulty regarding their sexuality, support for women and couples experiencing sexual difficulties as a result of breast cancer is lacking. The purpose of this dissertation was to develop and evaluate an online psychosexual intervention for couples experiencing sexual difficulties following breast cancer. The feasibility, acceptability, and preliminary impact of the intervention were evaluated using a single-arm, mixed-methods design, with participants completing questionnaires concerning sexual functioning, marital quality, and psychological adjustment at baseline, post-treatment, and three-month follow-up, along with satisfaction surveys and post-treatment interviews Participants' subjective experiences were triangulated with the quantitative data as a form of cross-verification, and to capture a more nuanced understanding of couples' experiences with this intervention and its delivery, along with its benefits. A sample of 14 couples ($N = 28$) received a 6-session psychosexual intervention delivered via videoconferencing (eTherapy). The intervention was found to be feasible and acceptable, as demonstrated by high retention, treatment adherence, and satisfaction. There was also evidence to suggest that the intervention was effective at improving sexual functioning and satisfaction, although decreasing effect sizes at 3-month follow-up point towards a progressive loss of gains on a number of measures over time. The use of eTherapy was widely accepted by participants, who highlighted several advantages of this modality. Overall, the results support the effectiveness of this eTherapy psychosexual intervention for couples affected by breast cancer. Emerging considerations for researchers and clinicians involved in the evaluation and implementation of psychosexual interventions, as well as in the provision of eTherapy, are also introduced.

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Chapter 1: Introduction

Excluding non-melanoma skin cancers, breast cancer is the most commonly diagnosed cancer among Canadian women, accounting for 25% of all cancers with an estimated one in eight women receiving a breast cancer diagnosis in her life time (Canadian Cancer Society, 2018). Fortunately, due to advances in detection and treatment, the five-year survival rate is relatively high, at 87% (Canadian Cancer Society, 2018). While survivorship rates are encouraging, this also means that a large proportion of women are living with the residual physical and emotional side effects that result from breast cancer and treatment (Amoyal, Nisotel, & Dizon, 2015).

"Although studies show that the overall quality of life of [breast cancer] survivors is quite good (especially in long-term survivors), a significant proportion of patients remain at risk for persistent or worsening symptoms, including symptoms related to sexual health" (Dizon, Suzin, & McIlvenna, 2014, p.203). Most breast cancer survivors, even those at low risk for overall psychological distress, report difficulties in some areas of sexuality for at least three years following diagnosis and treatment (Dizon et al., 2014; Henson, 2002; Karabulut & Erci, 2009; Krychman & Katz, 2012; Rowland et al., 2009; Tan, Waldman, & Bostick, 2002). Diagnosis and treatment of breast cancer have been associated with lower levels of sexual desire and interest, decreased sexual arousal, as well as alterations or cessation of orgasms (Henson, 2002; Ganz et al., 1996), which can have negative repercussions for sexual and intimate relationships of couples affected by breast cancer. Correspondingly, there is a growing body of evidence to suggest that alterations in sexuality, including declines in sexual functioning and satisfaction, are among the most common and most distressing problems experienced by breast cancer survivors and their partners (Dizon et al., 2014; Harirchi,

Montazeri, Bidokhti, Mamishi, & Zendehdel, 2012; Male, Fergus, & Cullen, 2016; Thors, Broekel, & Jacobsen, 2001).

Given that the majority of studies examining sexual dysfunction have focused on traditional forms of sexual activity (i.e., vaginal-penile intercourse) and/or frequency of intercourse, the exact prevalence of sexual dysfunction and distress among breast cancer survivors is not well known, but is estimated to range from 21-94% (Cebeci, Yangin, & Tekeli, 2010; Dizon et al., 2014; Karabulut, & Erci, 2009; Male et al., 2016). While physiological and/or physical changes such as decreased lubrication and pain during intercourse contribute to sexual dysfunction, sexuality is also influenced by a number of psychological and socio-cultural factors (Cayan et al., 2004; Cebeci, Yangin, & Tekeli, 2010; Yoshida, Li, & Odette, 199l; Garrusi, & Faezee, 2008; Nobre, & Pinto-Gouveia, 2006). Body image, femininity, desirability, sexual interest, attitudes towards sex and sexuality, as well as partner communication and support, have all been found to impact sexual functioning in breast cancer survivors (Henson 2002; Karabulut, & Erci, 2009; Male et al., 2016). Accordingly, it has been posited that a high proportion of sexual problems experienced by couples affected by breast cancer may be due to psychological rather than physiological/physical issues (Taylor, Harley, Ziegler, Brown, Velikova, 2011).

Despite the well-established evidence that many breast cancer survivors encounter some degree of difficulty regarding their sexuality, these issues are rarely addressed by health care providers (Dizon et al., 2014; Falk & Dizon, 2013; Karabulut & Erci, 2009; Male et al., 2016; Lewis et al., 2012; Ussher, Perz, & Gilbert, 2012). In fact, even when health care providers sense that their patients are experiencing sexual problems, and that counseling surrounding these issues should be provided, there remains a consistent lack of proactive

communication on sexual matters (Henson, 2002; Incroccri, 2011). Constraints on clinic time, personal discomfort with discussing sexual matters, along with lack of knowledge and available resources for managing sexual problems, have all been cited as reasons for not addressing sexuality in a medical setting (Karabulut, & Erci, 2009; Taylor et al., 2011).

To date, few interventions have been designed to address sexual problems in couples affected by breast cancer (Caroll, Baron, & Caroll, 2016; Taylor et al., 2011). Given the overwhelming evidence that many couples experience sexual difficulties[1] following breast cancer, there is a need to develop and empirically evaluate sexual counseling interventions for breast cancer survivors and their partners. The following study endeavoured to fill this gap through the design and evaluation of a couples-based psychosexual intervention delivered via videoconferencing. The following sections will briefly explain the research that lead to the development of this study including: a) an overview of the factors that contribute to the development and maintenance of sexual difficulties in women and couples affected by breast cancer, b) a review of previous couples-based interventions for sexual difficulties following breast cancer, and c) a rationale for the delivery of this novel intervention using videoconferencing software. Also outlined are the research objectives and hypotheses.

Mechanisms of Sexual Dysfunction in Breast Cancer

Emerging over the past few decades, literature has documented a range of physical and psychological changes that can adversely alter a woman's sexual health and well-being following breast cancer. In a recent review examining the impact of breast cancer and associated treatments on sexuality and intimate relationships, Male, Fergus and Cullen (2016) sought not only to identify the factors that contribute to alterations in sexual functioning, but to

[1] For the purposes of this study, sexual difficulties are conceptualized as altered sexual functioning and decreased satisfaction with the sexual relationship.

improve our understanding of *how* these factors alter sexual identities and relationships. The authors found that while trends in the literature exist with respect to the negative impact that breast cancer can have on sexuality, it is also evident that the ways in, and degree to which, breast cancer and treatment affect sexual functioning are influenced by a variety of individual and contextual factors. Thus, in addition to outlining the physical and psychosocial mechanisms through which sexual and intimate relationships are impacted by breast cancer, the following sections highlight the ways in which sexual dysfunction develops and is maintained through unique and nuanced interactions of said mechanisms.

Physiological and physical changes.

From a physiological and/or physical standpoint, chemotherapy is thought to have the most significant and detrimental impact on the sexual functioning of breast cancer survivors (da Mata Tiezzi et al., 2017), with women receiving chemotherapy reporting significantly higher incidences of sexual dysfunction and distress than women who have not received chemotherapy (Arora et al., 2001). In a study comparing the sexual outcomes of women who had received chemotherapy versus those who had not, Young-McCaughan (1996) found that those treated with chemotherapy were more likely to report vaginal dryness, painful intercourse, and difficulties with orgasm. Similarly, Ganz and colleagues (1998) found that among women 1-5 years post-treatment, sexual problems were more common in women who had received chemotherapy. Research also suggests that the detrimental impact of chemotherapy on sexual functioning may persist over time, such that long term survivors (i.e., more than five years) have reported significant decreases in libido, ability to relax and enjoy sex, arousal levels, and orgasm quality or quantity (Broeckel, Thors, Jacobsen, Small, & Cox, 2002). Not surprisingly then, women treated with chemotherapy therapy are often significantly

less satisfied with their sex lives (Arora et al., 2001; Gopie ter Kuile, Timman, Mureau & Tibben, 2014). Chemotherapy is associated with abrupt and premature menopause, with multiple side effects impacting sexual functioning and satisfaction. In a survey of nearly 2000 women, 28% identified chemotherapy induced menopause and associated physical changes including vaginal dryness (63%), hot flushes (51%), and weight gain (48.8%), as having been particularly disruptive to their sexual functioning. Age was also found to play an important role in the level of sexual dysfunction, with premenopausal women reporting more prominent disruptions in their sexual functioning than postmenopausal women (Lindley, Vasa, Swyer, & Winer, 1998). Although premenopausal and perimenopausal women appear to be confronted with higher rates of sexual impairment, postmenopausal women certainly do not remain unaffected. To the contrary, postmenopausal women who are required to cease hormone replacement therapy (e.g., estrogen replacements) due to hormone receptor positive breast cancer are likely to reexperience the aforementioned menopause related side effects (Kaplan, 1992).

Women diagnosed with hormone receptor positive breast cancer often receive adjuvant hormonal treatments in order to reduce their risk of recurrence. Because hormonal treatments, such as Tamoxifen, work to block the effects of estrogen on the body, the sexual side effects associated with this treatment are similar to, and potentially worse than, those associated with chemotherapy. Moreover, women with hormone positive breast cancer are often required to continue taking the treatment for up to five years post diagnosis (Early Breast Cancer Trialists' Collaborative Group, 1998). Accordingly, there is evidence to suggest that breast cancer survivors treated with adjuvant hormonal therapy may experience elevated rates of sexual dysfunction. For instance, women treated with hormonal blockers in combination with

chemotherapy, or with chemotherapy and radiation, exhibit greater sexual impairments than women treated with chemotherapy and/or radiation alone, with women receiving all three forms of treatment at a six-fold increased risk of lubrication and satisfaction disorders (Safarinejad, Shafiei, & Safarinejad, 2013). Additionally, Gopie and colleagues (2014) found that among women treated with chemotherapy, radiation, and hormone blockers, the latter was independently related to lower sexual relationship satisfaction.

Although not directly impacting sexual health and functioning, other treatment-related physical changes have also been linked to sexual difficulties and distress, including nausea, fatigue, pain, sensitivity, altered sensation, as well as restricted mobility (Bakewell & Volker, 2005). Women with more invasive forms of breast cancer typically have some or all of their lymph nodes removed during their breast surgery. Lymph node dissection has been associated with side effects that range from temporary to long lasting, including lymphedema (water retention and swelling in the affected area), shoulder disability, along with pain and mobility issues, all of which can alter a woman's sexual identity, functioning, and relationship (Katz, 2007; McWayne & Heiney, 2005).

Body image and sexual identity.

Although some changes to sexual functioning are the direct result of physiological and/or physical changes, there is evidence to suggest that psychological and relational changes also play a prominent role. Alterations in body image and self-esteem, along with reduced feelings of desirability and femininity, have all been linked to a decrease in desire for physical intimacy, along with subsequent changes to sexual and relational dynamics (Carver et al., 1998; Fallbjörk, Rasmussen, Karlsson, & Salander, 2013; Fingeret, Teo, & Epner, 2014; Rowland et al., 2000; Woertman, & Van den Brink, 2012). The physical and functional

changes that arise as a result of breast cancer treatment greatly impact how a woman experiences and perceives herself in her body, thus altering her confidence and identity as a sexual person. Relative to their precancer bodies, many breast cancer survivors report feeling less attractive, are dissatisfied with their bodies, and experience difficulties looking at their naked bodies following treatment (Fallbjörk, et al., 2013; Koçan & Gürsoy, 2016; Male et al., 2016). Poorer body image decreases perceived desirability and sexual attractiveness, and is directly associated with decreased sexual functioning and satisfaction in breast cancer survivors (Ganz, 1999; Male at al., 2016; Ussher et al, 2012). In fact, Fobair and colleagues (2006) found that after controlling for socio-demographic characteristic, disease stage, surgical and/or adjuvant treatments, as well as with physical and psychosocial factors, lower body image was positively correlated with sexual dysfunction and distress. Correspondingly, in a survey of 1956 women diagnosed with breast cancer, 51% attributed changes in their sexual well-being to feeling unattractive, 44% to feeling uncomfortable exposing their bodies, and 38% to having lost self-confidence (Lindley, Vasa, Swyer, & Winer, 1998). Bloom et al. (1998) also found that women interviewed 6-7 months post-diagnosis report having lower body image satisfaction than those interviewed soon after their diagnosis, suggesting that these problems not only persist, but potentially worsen over time.

Although the degree and mechanism through which a woman's body image is altered by breast cancer is a deeply personal and nuanced experience, there are some trends in the literature with respect to the relationship between breast cancer treatment, body image, and altered sexual functioning. Loss (or partial loss) of a breast, hair loss, weight gain, loss of fertility, and lymphedema have all been found to negatively impact body image in breast cancer survivors (Choi et al., 2014; Fobair, Stewart, Chang, D'Nonfrio, Banks, & Bloom,

2006; Paterson, Lengacher, Donovan, Kip, & Tofthagen, 2016; Rosenburg et al., 2013). Despite the large body of evidence that alterations resulting from breast surgery are associated with sexual problems, findings remain mixed regarding the impact of surgery type (e.g., lumpectomy, mastectomy, mastectomy with reconstruction) on sexual functioning. While some researchers have found that women who undergo breast conserving surgery (e.g., lumpectomy) have fewer sexual problems than women who undergo mastectomies, others have found no differences between surgery type (Male et al., 2016). For instance, Schover and colleagues (1995) found that women who have partial mastectomies report having more pleasure and frequency of breast caressing during sexual activity in comparison to women who have mastectomies with immediate reconstruction. On the other hand, Meyerowitz, Desmond, Rowland, Wyatt, & Ganz (1999) found that changes in comfort with sexual touching of the breast were not associated with surgery type or with having had reconstructive surgery. While Pérez and colleagues (2010) found that women who received a mastectomy were nearly three times more likely to report sexual problems than women who received a lumpectomy, Wapnir, Cody, and Greco (1999) found no differences in ratings of intimacy and sexual satisfaction between women who had received lumpectomies versus mastectomies. These contrasting findings likely reflect the subjective and individual ways in which women experience their bodies and sexual identities, such that no two women are impacted in the same way. Despite the inconsistent findings with respect to the relationship between surgery type and degree of sexual difficulties, one thing is clear: scarring, deformity, and/or absence of a breast all have far reaching consequences for breast cancer survivors and their partners (Male et al., 2016; Katz, 2007).

Chemotherapy induced alopecia (hair loss) is consistently ranked among the most

distressing side effects of breast cancer treatment, and adversely impacts body image (Choi et al., 2014; Lemieux, Maunsell, & Provencher, 2008; Trusson, & Pilnick, 2017). Given the challenges that hair loss poses to a woman's conceptualisation of femininity and attractiveness, it is no surprise that over one quarter of partnered breast cancer survivors report that alopecia related declines in body image contribute to their sexual problems (Fobair et al., 2006). For many women, hair loss is not limited to the scalp, and it is important to consider the implications of hair loss in other areas of the body on sexuality, such that loss of pubic hair can also affect a woman's identity as a sexual being (Katz, 2007). Although hair regrowth typically occurs once chemotherapy has ended, it is not uncommon for the color and structure of the hair to be altered, thus potentially prolonging the negative impact of hair loss on a woman's body image and self-esteem (Shaw & Boyle, 2017). Weight gain in breast cancer survivors is also well established in the literature, with 50%-96% of women experiencing significant weight gain after treatment (Rimer & Winer, 1997). Weight is an important part of body image for many women, and is closely connected to sexual self-schema and perceptions of sexual attractiveness (Katz, 2007). Correspondingly, weight gain has been associated with a decrease in sexual satisfaction among breast cancer survivors (Speet et al., 2005).

Partner and dyadic adjustment to altered bodies.

In addition to altering a woman's perception and experience of herself as a sexual being, the physical and psychological changes associated with breast cancer treatment often cause disruptions in a partner's experiences of sexual intimacy. Moreover, how couples navigate these challenges, both individually and as a collective, have implications for the development and maintenance of sexual problems.

In a systematic review, Rowland and Metcalfe (2014) explored men's experiences of,

and reactions to, their partner's altered physique and body image after breast cancer. The authors found that while the majority of men acknowledge that their sexual relationship has been negatively impacted, they are generally accepting of their partner's altered bodies. Although some men do have negative reactions to the physical changes in their partner's body, including perceiving their partners as less attractive and or less feminine, being less sexually attracted to their partners, and not wanting to touch them or engage in intercourse, these reactions appear to be less common (Rowland & Metcalfe, 2014). To the contrary, men frequently report that these changes do not affect how they feel about their partner and/or that they do not see their partner as less desirable. In fact, trends point towards a discordance between men's and women's perceptions of the altered body, such that men generally adopt a positive and supportive view of their partner's body, while women perceive themselves less favourably than their partners (Rowland & Metcalfe, 2014). In a qualitative investigation of couples' experiences with breast cancer (Loaring et al., 2015), all women interviewed spoke of wanting to 'cover up' in front of their partners, having lost confidence in being naked with them, and anticipating that their partners would see them as different or less attractive. On the other hand, men's perceptions of their partners were quite favourable, with men emphasizing sustained sexual interest in their spouse. While the women were aware of their partner's positions, they endorsed difficulties accepting their reassurances. Although men generally endorse understanding, acceptance, and continued attraction to their partners, they are not unaffected by the disruptions to their sexual relationship, with many men reporting a sense of loss and sadness due to the shift in physical intimacy. Men have also reported being upset by their partner's attempts to hide their bodies, as it prevents them from sharing in the breast cancer experience (Rowland & Metcalfe, 2014).

The impact of altered bodies and identities on women and their spouses is unique to each relationship, and couples' sexual dynamics are influenced by both partners' attempts to navigate these changes. All too frequently, sexual relationships are marred by avoidance that can become cyclical in nature and perpetuate problems with sexual functioning and satisfaction. Initially, breast cancer survivors may avoid sexual intimacy due to fear of rejection, while spouses may avoid initiating sex as a way of protecting their partner from pain or physical damage (Katz, 2007; Rowland and Metcalfe, 2014). Although avoidance functions to protect against discomfort, it can also reinforce fears and assumptions, and ultimately lead to further avoidance of physical intimacy. Women may perceive their partner's lack of approach and initiation as an indication of rejection, causing them to withdrawal even further. Likewise, men may interpret their partner's lack of initiation as a sign of reticence or discomfort to be physical, and avoid further attempts at sexual intimacy so as not to create any undue pressure. Sadly, couples' avoidance of sexual intimacy can lead to a reduction of other forms of physical affection (e.g., kissing, cuddling) for fear that they may be interpreted as sexual cues. Left unaddressed, couples' withdrawal from sexual and/or physical intimacy can have negative implications for emotional intimacy and connection.

In couples who are sexually active, women's uncertainty about a partner's reactions, along with men's uncertainty about their partner's preferences or comfort levels, also influence the ways in which they interact with one another sexually. For example, women who undergo breast surgery, including reconstruction, often experience loss of or altered sensation in their breast (Schover et al., 1995; Wilmoth & Ross, 1997). In response, partners may feel that caressing the reconstructed breast would not have any benefit, and therefore avoid touching the affected breast. Partners may also be reluctant to touch the affected breast during sex for fear

of causing pain and/or discomfort (Loaring et al., 2015; Rowland and Metcalfe, 2014). Although men may accurately perceive that their partner is no longer comfortable in showing her body (Rowland and Metcalfe, 2014), in the absence of communication, they must rely on assumptions as they consider their partner's feelings, comfort levels, and preferences during sex, and may fumble in their attempts to navigate sexual interactions in the context of these changes. Consequently, women may interpret their partner's hesitation, discomfort, and/or lack of interaction with the breast as a rejection (Katz, 2007).

Communication is associated with better dyadic adjustment to the sexual changes following breast cancer, and can play an important role in alleviating couples' sexual difficulties (Anllo, 2000; Takahashi & Kai, 2005). Although couples surveyed acknowledge the importance of communication for effective coping and adjustment to the sexual changes associated with breast cancer, both partners can experience difficulties and a reluctance to discuss certain topics, and/or are selective about the topics they choose to discuss (Loaring et al., 2015; Rowland & Metcalfe, 2014). Couples may also avoid discussing difficult topics in an effort to protect each other from emotional discomfort or pain (Emilee, Ussher, & Perz, 2010).

In one qualitative study of couples' experiences with breast cancer, women reported wanting to talk to their partners about how they felt about their bodies and sexual relationship, but shared that their discomfort in doing so compelled them to avoid said discussions despite having supportive partners. Some men experienced difficulties talking about the impact of breast cancer on their own psychological well-being for fear of burdening their partner. Other men found it difficult to talk about sex or their feelings towards their partner's bodies, particularly when their partners were already upset by this (Rowland & Metcalfe, 2014). As a

result of, and in an attempt to avoid further discomfort, couples report pulling away from each other and, consequently, having less verbal and emotional intimacy. Closed communication is also associated with conflict and poor psychological well-being in couples affected by breast cancer (Rowland & Metcalfe, 2014), while couples who are able to discuss and renegotiate their sexual practices are better able to manage and cope with the changes to their sexual relationship (Emillee et al., 2010)

Notwithstanding these relationship challenges, partners play an important role in the sexual functioning of women recovering from breast cancer treatment, such that partner emotional involvement is a strong predictor for women's sexual adjustment after breast cancer (Loaring, Larkin, Shaw, & Flowers, 2015), while a partner's difficulties understanding the changes and processes associated with breast cancer treatment and recovery are associated with an increase in sexual problems (Meyerowitz et al., 1999; Fobair et al., 2006; Ganz et al., 1996, 1996; Lindley et al., 1998). Emillee and colleagues (2010) identified the quality of a woman's relationship as one of the most important and consistent predictors of sexual satisfaction, sexual functioning, *and* sexual desire after breast cancer. In fact, relationship quality was found to be a stronger predictor than physiological, hormonal, and physical changes associated with cancer treatment. Correspondingly, an evaluation of sexual functioning in breast cancer survivors found that while erotic cues had less effect on eliciting a sexual response, romantic cues increased sexual desire, suggesting that intimacy, communication, and partner support may be more important than physical passion (Ganz et al., 1999). Although intimacy and relationship quality prior to breast cancer may influence the degree to which couples experience problems in their sexual relationship, the aforementioned sections highlight the reciprocal relationship between intimacy and sexuality, and how one can strengthen or

diminish another.

Interventions for Sexual Dysfunction in Couples Affected by Breast Cancer

To date, few interventions have been designed to address sexual problems in couples affected by breast cancer, let alone test their efficacy. Moreover, many interventions that do exist have focused on the physiological and/or physical components of sexual dysfunction, with less emphasis on the underlying psychosocial concerns (Krychman & Katz, 2012; Spears, Robinson, & Walker, 2017; Taylor, Harley, Ziegler, Brown, Velikova, 2011). In the first systematic review of interventions for sexual dysfunction in breast cancer survivors, Taylor and colleagues (2011) identified 21 interventions that fell into one of three main categories: exercise, medical, and psycho-educational / counseling. Of the 17 psychoeducational / counselling interventions reviewed, only six were designed specifically to address sexual difficulties in couples and included four couples-based interventions (Baucom et al., 2009; Chirstensen, 1983; Kalaitzi, Papadoulos, Michas, Vlasis, Skandalakis, & Filippou, 2007; Scott, Halford, & Ward, 2004), one group-based intervention (Rowland et al., 2009), and one peer counseling intervention (Schover et al., 2006). Although the group and peer counseling interventions were designed with the intention of addressing sexual difficulties in *couples,* the interventions themselves were delivered to breast cancer survivors only. The remaining 11 studies reviewed evaluated sexual health outcomes in the context of broader interventions designed to improve psychosocial adjustment and quality of life in breast cancer survivors.

Similar results were found in a second review, which yielded 34 studies consisting of vaginal (e.g., lubricants, dilators), systemic (e.g., endogens, antidepressants), physical therapy (e.g., physical activity, pelvic floor training), counselling, and/or educational interventions (Seav et al., 2015). Of the 17 counselling and educational interventions reviewed, ten targeted

sexual functioning as a primary outcome, whereas the remaining seven included sexual health outcomes as part of a broader psychosocial adjustment intervention. A closer examination of the ten studies targeting sexual health as a primary outcome revealed that nine of these interventions were designed exclusively to address sexual difficulties, with the remaining study focusing on improving menopausal symptoms. Of the nine interventions specifically targeting sexual functioning, only four were couples-based (Baucom et al., 2009; Christiansen, 1983; Kalaitzi et al., 2007; Scott, Halford, & Ward, 2004), while two were group-based (Jun, Kim, Chang, Oh, Kang, & Hang 2011; Rowland et al., 2009), two were peer support-based (Schover et al., 2006; Schover et al., 2011), and one was internet-based (Schover, Yuan, Fellman, Odensky, Lewis, & Martinetti, 2013).

The overall findings of both reviews were similar, particularly with respect to the effectiveness of interventions that focus on sexual rehabilitation. For instance, Seav et al. (2015) found educational and counselling interventions specifically targeting sexual dysfunction to be associated with consistent improvements in various aspects of sexual health. Similarly, Taylor et al. (2011) found couples-based, psychoeducational interventions that included an element of sex therapy to be the most effective. Although not exclusive to breast cancer, a third review found that couples-based interventions were more successful at enhancing women's sexual adjustment and body image after cancer than individually-based interventions (Scott & Kayser, 2009).

In a more recent review, that also specifically examined couples-based interventions for sexual difficulties following breast cancer, Caroll, Baron, and Caroll (2016) identified and evaluated five experimental or quasi-experimental clinical trials, all of which were associated with improved sexual well-being in breast cancer survivors and their partners. The

interventions evaluated in this review, which overlap with couples-based interventions identified in the two previous reviews, are summarized below.

In the earliest couple-based intervention, Christensen (1983) examined the impact of a 4-week program on psychosocial discomfort for couples ($N = 20$) who were 2-3 weeks post mastectomy. Session topics included psychoeducation surrounding mastectomy, exploration of the impact of the mastectomy on both partners and their relationship, communication exercises, and behavioural practices. The intervention was found to increase sexual satisfaction and reduce emotional discomfort for both partners, and was the first study to suggest that brief, couples-based interventions could effectively improve sexual functioning in couples affected by breast cancer. Despite the promising findings of this early intervention, some limitations should be noted, particularly with respect to generalizability. These include, small sample size, sample homogeneity with respect to treatment type (mastectomy only) and cancer trajectory (2-3 weeks post treatment), as well as limited follow-up (one-week post-treatment).

Kalaitzi, Papadopoulos, Michas, Vlasis, Skandalakis, and Filippou (2007) examined the impact of a brief psychosexual intervention for couples ($N = 20$) undergoing simple mastectomy. The intervention consisted of six bi-weekly sessions, the first of which took place while women were in the hospital recovering from surgery. Session topics included mastectomy debrief, communication, sensate focusing, and body image work. Although partners were present for each session, outcome measures were only completed by breast cancer patients. Results showed that in comparison to women in the control group, women who received the intervention reported improvements in body image, initiation of sex, and orgasm frequency. The limitations of this study are similar to that of the previous study. An additional limitation includes the lack of sexual outcome measures completed by partners.

Scott, Halford, and Ward (2004) evaluated the effect of a couple-coping training program on cancer adjustment for women preparing to commence treatment for breast (n = 57) or gynecological cancer (n = 37) in comparison to an individual training program and a control group. The intervention consisted of five, 2-hour sessions (held in couples' homes) at the following time points: before and after surgery, 1- and 5-weeks post-surgery, and 6 months post-surgery. Session topics included psychoeducation about the impact of surgery, coping skills-training, challenging negative cancer-related cognitions, supportive communication, and sexual counselling. In comparison to the control group and the individual coping training program, the couples-based program improved supportive communication and sexual adjustment. Although both spouses completed measures pertaining to sexual functioning, the questionnaires provided to women were more comprehensive (e.g., 50 items) in comparison to the measures completed by men (e.g., 6 items). An additional limitation of this study relates to the inclusion of both breast and gynecological cancers, making it difficult to delineate the impact of the intervention on couples affected by breast cancer. That the sessions were delivered in the home creates an additional barrier to feasibility and replicability. Finally, although the intervention was delivered to couples, and that partners were encouraged to support each other, it has been criticized for its emphasis on teaching *individual* coping skills and cognitive restructuring rather than on dyadic coping and adjustment (Baucom et al., 2009).

In an attempt to build and improve upon previous studies, Baucom et al. (2009) evaluated a couples-based relationship enhancement intervention designed for women (N = 14) recently diagnosed with breast cancer, most of whom had completed active treatment (i.e., surgery, chemotherapy, radiation). The intervention consisted of six, bi-weekly sessions that included the following topics: approaching breast cancer as a couple, communication skills

building, promotion of healthy sexual adaptation and body image, meaning making, and growth. Effect sizes showed that couples who were randomized to the intervention had improved relationship adjustment and sexual functioning at post-treatment as well as at 12-month follow-up. A small sample size was the primary limitation of this study.

In the most recent study, Decker, Pais, Miller, Goulet, and Fife, (2012) evaluated the efficacy of a three-session, couples-based intervention for women ($N = 65$) who were pre- or perimenopausal, and who had been diagnosed with non-metastatic breast cancer within the last three to nine months. Couples were given the option of participating in either a face-to-face intervention, a telephone-based intervention, or questionnaire only (control) group. The intervention consisted of three, 60-minute sessions that were administered every 2-3 weeks, with session topics including communication, intimacy and sexual-wellbeing, as well as dyadic coping. Although the results did not yield any statistically significant differences, it did point towards several trends across time, with couples in both intervention groups reporting higher levels of perceived intimacy, dyadic adjustment, body image, and sexual functioning across time. Notably, the telephone-based intervention was found to be just as effective as the face-to-face intervention, with participants reporting high levels of satisfaction for both. Couples who elected to participate in the telephone-based intervention also appreciated the scheduling flexibility of this modality and not having to travel to a treatment site. In fact, some participants indicated that they would not have been able to participate in a face-to-face intervention. The telephone-based modality also provided couples with an additional element of privacy that increased comfort levels with the subject matter. Some participants indicated that communication may have been enhanced by face-to-face interactions, and suggested that a combination of phone and face-to-face would have been ideal.

Although not delivered to couples, a group-based intervention designed by Rowland et al. (2009) is noteworthy due to its primary design goal of improving the sexual well-being of women and couples affected by breast cancer. In this randomized control trial, the authors evaluated the efficacy of a 6-week, psycho-educational group program for partnered and unpartnered women ($N = 210$) with a diagnosis of stage 0-II breast cancer, who had completed active treatment (e.g., surgery, radiation, chemotherapy), and were 1-5 years post-diagnosis. The intervention was designed based on a conceptual model of the development of sexual dysfunction in breast cancer survivors (Ganz, Desmond, Belin, Meyerowitz, & Rowland, 1999), with session topics including body image and sexual anatomy, sexual attitudes, behaviours, sexual functioning enhancement, as well as communication. The results showed that women in the intervention group were more likely to report an increase in sexual satisfaction, as well as improvements in relationship adjustment and communication.

The interventions described above are promising with respect to addressing the needs of couples experiencing sexual difficulties following breast cancer. Despite notable strengths of some studies, none is without limitations. Although all of the studies included in the aforementioned reviews included sexual functioning and/or satisfaction as a primary outcome measure, some of the interventions were not designed exclusively to alleviate sexual difficulties, and focused more on improving dyadic adjustment and relational intimacy. For example, the primary aim of Christensen's study (1983) was to reduce couples' psychosocial discomfort, and the protocol did not include any sessions specific to sexuality. Although Scott et al. (2004) hypothesized that their intervention would promote better female body image and sexual adjustment, their intervention was focused on couple-coping, and only incorporated sexual counseling in one session out of five sessions. Likewise, despite their comprehensive

approach to promoting relationship enhancement in couples affected by breast cancer, and their deliberate attempts to improve upon previous studies methodologically (i.e., more comprehensive assessments, emphasising dyadic versus individual coping), sexual functioning was only addressed in one of six sessions in the intervention designed by Baucom and colleagues (2009).

Therefore, out of the five couples-based interventions reviewed, only two were designed specifically to address issues with sexual functioning. As described above, Kalaitzi et al. (2007) designed a brief psychosexual intervention for women (and their partners) undergoing mastectomy, with the first session administered in hospital immediately following mastectomy. A notable strength of this intervention was its focus on sexual functioning and its inclusion of multiple components associated with effective sexual counseling in couples affected by cancer, including communication, psychoeducation, sensate focusing, and body image work. Unfortunately, its generalizability is limited to women with early stage breast cancer, who did not receive any other treatments, and who were in the earliest stage of treatment and recovery. Additionally, because outcomes were only measured in breast cancer patients (and not their partners), partner outcomes were not represented in the results. As previously described, problems with sexual functioning and satisfaction have been shown to develop and worsen well past the first year of breast cancer treatment (Ganz et al., 1996). Thus, although the study was affective in alleviating sexual difficulties up to three months post mastectomy, and demonstrates promise as an early intervention to minimize sexual dysfunction, it overlooks a broader cohort of couples affected by breast cancer, particularly those who are already experiencing sexual difficulties. Given the numerous decisions that couples must make in the early stages of cancer diagnosis and treatment, along with the stress

associated with this (Decker et al., 2012), early interventions may not be appropriate for couples who might not be prioritizing (or even considering) their sexual relationship in these early stages. Accordingly, in their evaluation of a psychosexual program that also aimed to prevent sexual dysfunction through early intervention, Decker and colleagues (2012) opted to initiate the intervention at three to nine months post diagnosis. Although results were not statistically significant, both intervention groups (e.g., face to face and telephone) showed similar trends for improvement in comparison to the control group. The findings of this study also provide evidence in support of psychosexual interventions delivered remotely as an alternative to face to face therapy.

As described in the summaries above, there is considerable variability with respect to sample characteristics, intervention design and delivery, methodology, as well as outcome measures used in the development and evaluation of psychosexual interventions for couples affected by breast cancer. Although existing interventions demonstrate promise for addressing sexual difficulties in couples affected by breast cancer, their limitations highlight a need for more interventions that are applicable to couples who are currently experiencing problems (versus preventative interventions) and can be generalized to women at all stages of breast cancer and who have undergone multiple treatments.

Online Delivery of Psychosexual Interventions

Videoconferencing-based psychotherapy (eTherapy) is increasingly being used in a variety of health care settings, and there is a growing body of literature supporting the use of eTherapy as a feasible and effective alternative to therapy delivered in office (Lawrence, 2010; Richardson, Frueh, Grubaugh, Egede, & Elhai, 2009). In addition to convenience and outreach for individuals living in remote areas, eTherapy interventions can be particularly advantageous

for improving accessibly of specialty health services that may not be widely available (Miller, 2001). eTherapy has been used with a range of therapeutic models and with diverse populations, (Backhaus et al., 2012), and there is evidence to suggest that eTherapy interventions are beneficial to and well received by couples and/or cancer populations (Bischoff, 2004; Collie et al., 2007; Larson, Rosen, & Wilson, 2018; Porter, Keefe, Baucom, Olsen, Zafar, & Uronis, 2017; Wrape & McGinn, 2018). For instance, in their systematic review and meta-analysis evaluating the effect of eTherapy interventions on quality of life of cancer patients, Larson and colleagues (2018) found that eTherapy interventions were associated with statistically significant improvements in quality of life, and were just as effective as in-person interventions. A study examining the impact of an eTherapy intervention for improving communication in couples facing gastro intestinal cancer found the intervention to be feasible, acceptable, and effective (Porter et al., 2017). The intervention also had higher retention and completion rates than its previously evaluated face-to-face counterpart. According to feedback from couples and therapists, the eTherapy format also enhanced the therapeutic alliance. Participants reported that the format allowed them to share personal aspects of their home life with the therapist (i.e., introducing a pet); some participants also reported feeling more comfortable discussing sensitive issues using eTherapy in comparison to in-person therapy. Therapists indicated that levels of rapport felt as high or higher than in-person sessions.

Although scarce, existing telepsychology interventions for improving sexual functioning in couples affected by cancer support the feasibility and acceptability of these alternatives to in-person therapy. For example, in one telephone-based intervention for physical intimacy and sexual concerns following colorectal cancer, couples rated the

intervention as important and helpful in addition to showing improvements on all objective measures of sexual and relationship outcome (Reese et al., 2014). In another randomized trial of internet-based versus face-to-face sexual counselling for couples affected by prostate cancer (Schover et al., 2012), it was found that both modalities produced equally significant gains in sexual functioning and satisfaction. Moreover, recruitment rates for couples invited to participate in the internet-based intervention, which depended on email for contact with the therapist, were three times faster than for the in-person study arm, reflecting a possible preference for interventions that are delivered remotely. Although the latter two interventions were not delivered using video conferencing software, these findings provide additional support for the rationale and possible advantages of interventions delivered via eTherapy.

The decision to deliver the present intervention using videoconferencing software was made under careful consideration with the primary goal of reducing participant burden (i.e., travel time and associated costs) and enhancing outreach (Mctavish, Gustafson, Owens, Wise, Taylor, & Apantaku, 1994; Shaw, Gustafson, Hawkins, McTavis, & McDowell, 2006.) In addition to the aforementioned benefits, this mode of delivery aims to minimize barriers that may be especially prominent in couples affected by breast cancer including coordinating schedules and arranging for childcare, along with possible mobility issues associated with cancer treatment and recovery (i.e., pain and fatigue).

Study Rationale

The current study proposed to evaluate a novel psychosexual intervention delivered via videoconferencing for couples affected by breast cancer, with a primary focus on enhancing sexual relationships by reducing sexual dysfunction and improving sexual satisfaction. This investigation is warranted considering: 1) a large proportion of couples experience sexual

problems following breast cancer treatment; 2) difficulties with intimacy and sexuality tend to extend past the 1-year post-treatment point; 3) partners can play an important role in helping to reclaim sexual function after breast cancer; 4) couples-based interventions designed specifically to address sexual problems after breast cancer are lacking; 5) existing support for sexual difficulties may not be readily accessible, especially for couples living outside of large metropolitan areas where these services are more likely to be available; 6) remote delivery of psychosexual interventions has the potential to increase couples' access to a much needed resource.

Aims and Hypotheses

Primary aims.

1) To evaluate the feasibility and acceptability of implementing and evaluating an online psychosexual intervention for couples experiencing sexual difficulties following breast cancer.
2) To provide preliminary evidence for the effectiveness of a couples-based psychosexual intervention on sexual functioning for breast cancer patients and their partners.
3) To describe the subjective experiences of couples completing the online psychosexual intervention.
4) To develop recommendations for the implementation of psychosexual interventions for couples affected by breast cancer delivered via eTherapy.

Hypotheses.

1) Couples will adhere to and complete the 6-week psychosexual intervention delivered via eTherapy.
2) Following completion of the program, participants will demonstrate improvement on measures of sexual functioning and satisfaction.

3) Following completion of the program, participants will demonstrate improvement on measures of dyadic adjustment and individual coping.

4) Participants will report positive, subjective experiences in completing the program.

Chapter 2: Methods

Intervention Development and Content

The intervention and study protocol were developed based on i) consultations with an interdisciplinary team of individuals with expertise in areas relevant to this project; ii) empirical research pertaining to the sexual difficulties and needs of women and couples affected by breast cancer (Henson, 2002; Karabulut, & Erci, 2009; Tan et al., 2002); iii) principles and practices of couples and sex therapy (Gottman & Silver, 2015; Greenberg & Goldman, 2008; Hertlein, Weeks, & Gambescia, Eds., 2009; Masters & Johnson, 1970); and iv) previous psychosexual intervention studies for cancer survivors (Kalaitzi et al., 2007; Rowland et al., 2009; Krychman & Katz, 2012; Taylor, Harley, Ziegler, Brown, Velikova, 2011). Consultations included individual and group meetings with health care professionals specializing in breast cancer (e.g., nurses, radiation oncologists, oncologists) and who work directly with breast cancer patients; clinicians and researchers versed in the area of intervention design, implementation, and evaluation; along with community-based organizations that provide support and resources to women affected by breast cancer. In addition to informing the intervention and study design, these consultations played an instrumental role in participant recruitment by supporting promotion of the study and/or through direct referrals.

Conceptual framework.

The current intervention was adapted from a previous couples-based intervention that combined brief couples therapy and sex therapy to address sexual problems in couples affected

by breast cancer (Kalaitzi et al., 2007), as well as a group-based psycho-educational intervention aimed at improving sexual well-being in partnered and unpartnered breast cancer survivors (Rowland et al., 2009). At the time the current intervention was developed, the aforementioned programs were the only interventions available in the literature that *exclusively* addressed sexual difficulties in couples affected by breast cancer. Although the latter study was delivered to women only (and did not include partners), its focus was on addressing intimacy and partner communication after breast cancer. In addition to consisting of six sessions, topics addressed by both programs included communication training, sensate focusing (described below), body image, and sexual attitudes/values. The combined adaptation of these interventions was a strategic decision based on evidence suggesting that couples-based approaches combining psychoeducation and sex therapy are most effective with respect to addressing sexual problems resulting from breast cancer (Seav et al., 2015; Taylor et al., 2011). Another advantage of these two interventions was their *primary* focus on sexual functioning and satisfaction, whereas previous interventions generally incorporated sexuality as one component of a more generalized program aimed at enhancing coping and survivorship (Taylor et al., 2011). In addition to the psychosexual interventions mentioned above, models that informed the development and delivery of this program included: (1) Acceptance and Commitment Therapy (Hayes, Strosahl, & Wilson, 1999); (2) Sensate Focusing (Masters & Johnson, 1970); and (3) The Physical Pleasure-Relational Intimacy Model of Sexual Motivation (Beck, Robinson, & Carlson, 2013).

Acceptance and Commitment Therapy.

Acceptance and Commitment Therapy (ACT) is an empirically validated intervention based on the premise that psychological distress develops as a result of emotional avoidance

and a failure to live in accordance with one's values (Hayes et al., 1999). Accordingly, ACT aims to decrease psychological distress through processes of acceptance, mindfulness, and values-based living, and by targeting experiential avoidance. ACT has shown considerable promise in the treatment of a variety of mental health issues including anxiety, depression, chronic pain, and substance abuse (Hayes et al., 1999; Smout, Hayes, Atkins, Klausen, & Duguid, 2012). There is also evidence to suggest that ACT can enhance both relationship and sexual satisfaction in couples, as well as improve quality of life in cancer patients (Arabnejad, Birashk, & Abolmaali Alhosseini, 2014; Buhrman et al., 2013; Feros, Lane, Ciarrochi, & Blackledge, 2013; Nezhad & Shameli, 2017; Peterson, Eifert, Feingold, & Davidson, 2009).

From an ACT perspective, relational distress and emotional distance stem largely from experiential avoidance of communication when previous communications have led to conflict, avoiding expressions of physical or emotional intimacy due to fear of rejection, and lack of engagement in joint activities that create meaning and shared memories (Peterson et al., 2009). Although avoidance often serves to protect against negative thoughts, feelings, and interactions within a relationship, it ultimately contributes to the development and maintenance of dysfunction within the relationship (Peterson et al., 2009). What's more, avoidance begets avoidance, which can lead to further relationship dissatisfaction and/or distress.

Given the multitude of adverse experiences reported by couples with sexual difficulties (i.e., physical pain and discomfort, decreased desire and arousal, difficulty achieving orgasm, body image issues), it stands to reason that couples engage in experiential avoidance of sex, intimacy, and communication, at least in part, to minimize and protect themselves against these adverse experiences. Accordingly, the core principles of acceptance, mindfulness, and values-based living served as major theoretical underpinnings to this intervention. Acceptance played

a particularly large role, whereby couples were encouraged to accept their current situation (i.e., changes and current limitations to their sex-life) and adjust their expectations and sexual activities accordingly, rather than ignore, reject, or fight against such changes. Couples were also encouraged to notice and accept their thoughts, feelings, and urges in the context of the intervention and assigned homework. Given that many couples are not able to engage in sexual activity in the same way they did before breast cancer and treatment, values-based living was used to help couples explore and engage in alternative ways of being sexual that are in line with what they enjoy and value. Finally, couples were encouraged to engage in mindfulness practices as a step towards reconnecting on a physical level, with an emphasis on appreciating the experience and sensations associated with being physically intimate. This was accomplished primarily in the context of Sensate Focusing (described below).

Sensate Focusing.

Sensate Focusing (SF) is a sex therapy technique designed by Masters and Johnson (1970) for the treatment of sexual problems, and aims to reduce sexual anxiety/distress by encouraging couples to focus on experience and sensations rather than on performance. In SF, couples are guided through stages of increasing physical contact and tactile closeness, with the goal being not to achieve orgasm (or even sexual arousal), but to have an appreciation of an entirely new set of sensual possibilities. "By mindfully being present to sensations in the moment, and refraining from forcing pleasure and arousal, clients can move towards the optimal intimacy they desire" (Weiner & Avery-Clark, 2014, p.307). Additional functions of SF include increasing communication about sexual/sensual needs, wishes, and desires; expanding couples' sensual and sexual repertoire; appreciating foreplay as a pleasurable activity in itself rather than a means to an end; increasing sexual desire and interest; and

creating positive relational experiences and interactions (Weeks & Gambescia, 2009). Please refer to Appendix H for a full description of SF and instructions provided to couples.

Physical Pleasure-Relational Intimacy Model of Sexual Motivation.

The Physical Pleasure-Relational Intimacy Model of Sexual Motivation (PRISM model) was developed by Beck, Robinson and Carlson (2013) who sought to understand the factors that distinguish couples who were successful in adjusting to sexual changes following treatment for prostate cancer versus those who were not successful. Major findings from their qualitative study that formed the basis for the PRISM model included: i) people are motivated to engage in sex primarily for the purposes of sexual pleasure and relational intimacy; ii) couples who engage in sex primarily for relational intimacy adjust better to sexual changes than couples motivated primarily by sexual pleasure; iii) no clear difference exists between men and women and the sexual values they endorse; iv) acceptance, flexibility, and persistence play a central role in successfully adjusting to changes in couples' sexual relationships (Beck et al., 2013; Beck & Robinson, 2015). As Beck and Robinson explain, sex can be valued for physical pleasure *and* relationship intimacy, which can be thought of as two separate dimensions rather than mutually exclusive constructs. Additionally, the value individuals place on sex for each of these two constructs exists on a continuum ranging from high to low. For example, while one individual may place high value on relational intimacy but less value on physical pleasure, another individual may place high value on physical pleasure and less value on relational intimacy. Individuals may also place high value on both constructs or low value on both constructs. Correspondingly, Beck and colleagues (2013) developed a dimensional matrix as a way of demonstrating the interaction between these two constructs and allowing individuals' motivations for engaging in sex to be plotted (see Figure 1). The PRISM model

and accompanying dimensional matrix were utilized in the current psychosexual intervention for three main purposes. First, each couple was presented with a copy of the PRISM model matrix and asked to rate the degree to which they value physical pleasure and relational intimacy in order to facilitate a discussion about pleasure and closeness, with the goal of increasing each partner's understanding of their own, and their partner's, sexual needs and values. Drawing upon the ACT model, couples were then guided through a collaborative exploration of alternative behaviors/activities that were in line with their pleasure and relational values. Finally, psychoeducation regarding acceptance, flexibility, and persistence was provided, with these elements being reinforced and encouraged throughout the entire intervention (refer to appendix G for further detail).

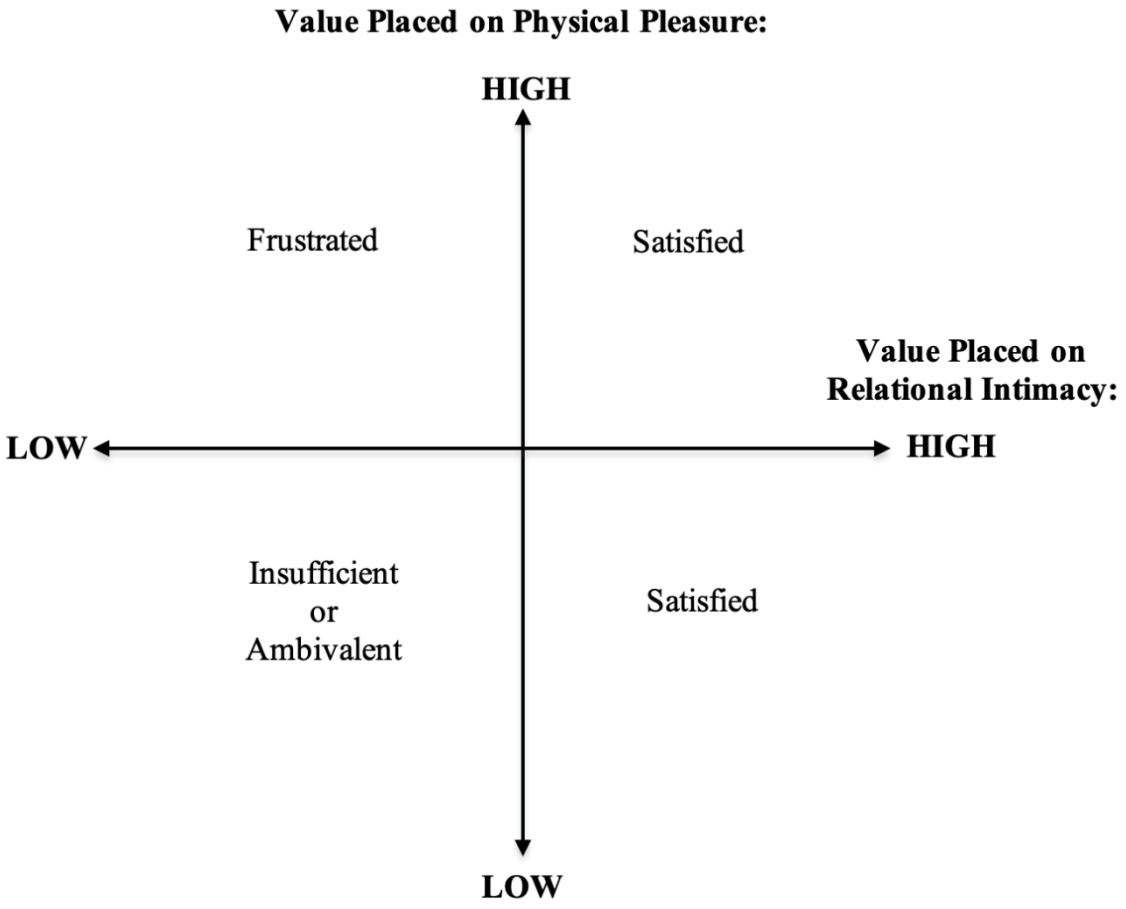


Figure 1. Physical Pleasure-Relational Intimacy Model of Sexual Motivation (PRISM Model). Adapted from "Sexual Values as the Key to Maintaining Satisfying Sex after Prostate Cancer Treatment: The Physical Pleasure–Relational Intimacy Model of Sexual Motivation." By A. M. Beck, J. W. Robinson, and L. E. Carlson, 2013. *Archives of Sexual Behavior, 42,* p. 1641

Pilot Couple

Prior to commencing with recruitment for the study, the intervention was piloted with a couple referred through the SHARE Sexual Health and Rehabilitation clinic at Sunnybrook Odette Cancer. The intervention was delivered in person, and feedback was obtained from the couple upon completion of the program. This was an important and necessary first step to gauge the impact and feasibility of the intervention, and led to improvements with respect to content, organization, and delivery. Specifically, the duration of each session was extended from one hour to 90 minutes in order to ensure that all pertinent material was addressed (i.e., check-in, homework review, session topic). In addition to introducing the homework at the end of each session, written handouts of the assigned homework were provided to couples via email. Perhaps the most significant improvement to the intervention was the introduction of Sensate Focusing (SF) during Session Two. Originally, SF was introduced in Session Five as a strategy for couples to use upon completion of the program. As part of their feedback, the pilot couple indicated that it would have been helpful to practice this exercise over the course of therapy with guidance and feedback from the facilitator. Given that SF was considered to be a crucial first step towards regaining physical intimacy, and could ultimately be used to monitor couples' progress throughout the intervention, the exercise was introduced in Session 2. By implementing this change, I was also better positioned to encourage, address, and discuss couples' progress towards rebuilding their physical/sexual relationship such that the extent to which SF was taken up by the couple served as a gauge for their reconnecting physically. Accordingly, a weekly review of couples' experiences with SF exercises allowed us to identify and discuss challenges/barriers to physical intimacy (e.g., finding time, physical or emotional discomfort, etc.), explore likes and dislikes of physical intimacy, incorporate reflections of past

sexual experiences in session, along with taking steps for moving forward. Finally, piloting the intervention also validated and reinforced the decision to incorporate certain elements into the intervention, particularly with respect to ACT, communication skill building, and a session dedicated to exploring couples' sexual values.

Intervention Protocol

The psychosexual intervention consisted of six, 1.5-hour sessions, delivered to each individual couple (versus a group program) on a weekly basis using video-conferencing software. Session summaries are described below. Refer to Appendix G for intervention manual.

Session overview.

Session 1. Session 1 focused on obtaining relevant background information related to the couple's sexual relationship, including functioning, satisfaction, preferences, etc., before and after breast cancer treatment; providing introductory psychoeducation regarding the impact of breast cancer on sexuality and sexual functioning; expectation and goal setting; and alliance building. The facilitator introduced the outline for Session 2, and couples were provided with homework in order to prepare them for the next session.

Session 2. Session 2 focused on communication skill building, whereby couples were taught to communicate their needs, thoughts, and feelings to their partner, empathically listen and attend to their partner, and support one another. Couples were guided through an "Intentional Dialogue" exercise (Hendrix, 1988), each taking turns as speaker and listener. Couples were provided with validation and corrective feedback, as well as the opportunity to debrief about the exercise. Couples were also introduced to Sensate Focusing, and provided with instructions for completing Stage 1.

Session 3. Session 3 focused on engaging couples in a dialogue about sex and intimacy, including an exploration of sexual attitudes, values, and expectations. This session was guided by the PRISM model (Beck et al., 2013), whereby each partner was encouraged to discuss the degree to which he or she values physical pleasure and relational intimacy, along with their definition of pleasure and closeness. For example, couples identified having dedicated alone time, being playful/carefree, the act of giving and/or receiving pleasure, or intimate 'pillow talk' as elements they valued about sex/intimacy. In addition to increasing each partner's awareness of the other's needs and values, a primary aim of this session was to identify and promote mutually defined needs and values with respect to their sexual relationship. Informed by ACT principles of acceptance and values-based living, couples were guided through a collaborative exploration of new and/or alternative ways of interacting that were in line with these values. Some examples included alternative ways of giving and receiving pleasure or enjoying physical touch (e.g., taking a bath or shower together, cuddling, giving a massage), scheduling dedicated time together (e.g., date nights, taking time in the day to check in), and encouraging sensual communication or interactions (e.g., talking about fantasies, flirting, kissing). Couples were also provided with psychoeducation about acceptance, flexibility, and persistence, along with the role of each principle in addressing their challenges and regaining a mutually satisfying sex life.

Session 4. Session 4 focused on the psychological and emotional impact of breast cancer, and how this impacted the couple's sexual relationship. Topics included body image, menopause, couples' response to the physical and sexual changes associated with breast cancer (e.g., loss of breast, loss of libido, etc.), and the experience of breast cancer diagnosis and treatment. A primary goal of this session was to increase couples' mutual awareness and

appreciation of their own, each other's, and their collective experience with breast cancer. Accordingly, this session also aimed to enhance intimacy and connection by facilitating couples' sense of shared identity/journey with respect to breast cancer. Couples were then provided with strategies for addressing their described challenges through the facilitation of brainstorming and psychoeducation based on their specific needs, values, desires, etc.

Session 5. Session 5 focused on problem solving and coping, whereby changes to women's sexual responsiveness and/or anatomy, as well as specific problems related to the couples' sex life were addressed. Couples were also provided with psychoeducation and practical strategies to enhance physical intimacy and sexual satisfaction. Topics included identifying and taking the first steps towards having sex, planning or scheduling sex, sharing initiation of sex, boundaries and expectations, modified sexual positions/activities based on couples' preferences and limitations, as well as the use of sex toys (e.g., vibrators), lubrication, and sexual aids.

Session 6. In Session 6, couples summarized what they had learned from the intervention; reflected on the changes they had noticed in their relationship, in themselves, and in their partners; identified strategies they found helpful and planned to continue using; and explored goals and plans for continuing with their forward momentum towards a mutually satisfying sexual relationship. Couples were also guided in a discussion of anticipated barriers/challenges to meeting these goals, and possible solutions/strategies for addressing these challenges (e.g., weekly check ins and/or review of program handouts). Couples were also provided with a consolidated handout of session topics and assigned homework, along with additional resources.

Program facilitation and supervision.

eTherapy sessions were delivered by a PhD Candidate in Clinical Psychology (K. Cullen), with clinical experience in oncology, and additional training and knowledge in couple's therapy, women's health, and sexual functioning. Sessions were delivered under the supervision of Dr. Karen Fergus, a licensed psychologist with over 20 years of experience in psycho-oncology and counseling couples affected by breast cancer, as well as experience in the development and evaluation of online interventions. Sessions were audio recorded and reviewed by K. Cullen and Dr. Fergus as part of the supervisory component of this study.

Confidentiality and security.

eTherapy sessions were delivered using VSee, a secure, encrypted videoconferencing software commonly used by health care providers practicing telemedicine. While issues related to eTherapy and videoconferencing are not directly addressed in the *Personal Health Information Protection Act, 2004* (PHIPA), *Privacy by Design* (PbD), a concept conceptualized by Ontario's Information and Privacy Commissioner, Dr. Ann Cavoukian, aims to address privacy issues related to remote home health care technologies (Cavoukian, Hoffman, & Killen, 2009; Health Information Protection Act, 2004). Using seven foundational principles (i.e., taking a proactive rather than reactive approach to privacy risks, embedding privacy into the design of a technology), PbD "offers a technology-neutral flexible framework which maximizes the ability of technology innovators to apply the [Fair Information Practices] to technology to protect individual privacy" (Cavoukian et al., 2009, p. 9). PbD has "gained widespread international recognition, and was recently recognized as a new global privacy standard" (Information and Privacy Commissioner, Ontario, Canada, n.d.). Accordingly, the selection of videoconferencing software for this study was guided by PbD to ensure that participants' privacy and confidentiality were maintained. For example, VSee software is

managed by a peer-to-peer architecture, such that video is streamed directly from end-point to end-point, and is neither intercepted, recorded, nor stored by the server. Second, the VSee software uses a level of encryption that ensures all eTherapy sessions remain confidential, thus adding another level of security. Among the videoconferencing software currently available and meeting criteria mentioned above, VSee was selected on account of its accessibility (available for download or as an app at no cost) and ease of use.

While many videoconferencing technologies, including VSee, allow health care providers to video record sessions, the sessions in this study were not video recorded using the software. Instead, sessions were audio recorded using a digital audio recorder, in the same manner that in-person counseling sessions would be recorded. Given that video recordings were not crucial to effective supervision, the priority was placed on optimizing privacy and confidentiality by using audio recordings only.

Each participant was assigned a unique participant ID, and questionnaires were sent in the form of password protected documents identified only by participant ID number. No identifying information was included in the questionnaires. Following each eTherapy session, couples were provided with supplemental materials (i.e., readings and homework) via email. All couples were made aware of the potential risks of corresponding via email.

Study Design

An exploratory, single-arm, mixed-methods design with concurrent triangulation strategy (Creswell, 2003; Jick, 1979) was employed to investigate the feasibility, acceptability, and preliminary effectiveness of a six-session online psychosexual intervention for couples affected by breast cancer. Questionnaires concerning sexual functioning and satisfaction, marital quality, and psychological adjustment were administered at three time points: baseline

(T0), post-intervention (T1), and at 3-month follow-up (T2). A brief satisfaction questionnaire was included at T1, whereby participants rated their satisfaction with the intervention and were provided with the opportunity to elaborate on their experiences using open-ended questions. Couples also participated in a semi-structured post-treatment interview. Questionnaires were completed individually, while post-treatment interviews were completed as a couple. Participant retention and treatment adherence were monitored as a measure of feasibility and acceptability. Quantitative data included descriptive summary statistics, repeated measures of sexual functioning, marital satisfaction, and psychological functioning, as well as measures of treatment satisfaction and perceived convenience. Qualitative data included information about participants' experiences with the intervention, which was extracted from open-ended written responses in the treatment satisfaction questionnaire (T1) and from post-treatment interviews. Quantitative data were triangulated with qualitative data in order to enhance the likelihood of obtaining trustworthy findings (Linccoln & Guba, 1985), and in order to provide a nuanced understanding of couples' experiences with the program.

The proposal for this study was reviewed by the Research Ethics Boards of Sunnybrook Health Sciences Centre, Princess Margaret Hospital (PMH), and York University, and approval was granted prior to commencing with recruitment (including pilot couple).

Participants and Recruitment

Inclusion and exclusion criteria.

Eligibility criteria for the women included a diagnosis of invasive breast carcinoma (non-metastatic) or ductal carcinoma in-situ within the last six years, and having undergone either a mastectomy or lumpectomy. Women were also eligible if they had undergone chemotherapy and/or radiation, or received adjuvant treatments (e.g., Tamoxifen, aromatase

inhibitors, Herceptin). In order to participate in the study, women were required to be at least one-month post-active treatment (e.g., surgery, radiation, chemotherapy); women currently receiving adjuvant treatment were considered to be eligible. Recruitment was limited to couples who had been in a committed relationship since before the cancer diagnosis. Couples must also have endorsed some degree of negative change in their sexual relationship (e.g., decline in frequency, quality, or satisfaction) as a result of breast cancer. Couples who had started a relationship during or after breast cancer treatment were excluded at this early stage in program development based on literature suggesting that these subgroups of couples may experience different and/or additional challenges and needs (Kurowecki & Fergus, 2013; Male et al., 2016). Correspondingly, same-sex couples were also excluded, as it was unclear if these couples represent a subpopulation with different experiences, challenges, and needs. This study also required that participants be fluent in written and spoken English, be 18-80 years of age, have convenient access to a computer with a reliable internet connection in a private setting, and have access to videoconferencing software (available for download at no cost). Web-cameras were to be made available to couples who did not have access to this technology.

Exclusion criteria were a mental illness that would interfere with the ability to participate (e.g., severe depression, actively suicidal, psychotic disorders), couples who planned to participate in couples or sex counselling during the study, and couples experiencing significant levels of relationship distress (e.g., presence of violence or abuse, significant conflict), in which case they were referred for counselling.

Sample demographics and medical characteristics.

Demographic information and clinical characteristics of the sample are summarized in Table 1. The average age of participants ($N = 28$) was 46.46 years ($SD = 7.79$, range 34–63),

with the average age of men being 47.35 years (*SD* = 8.17, range 36–63) and women being 45.57 years (*SD* = 7.3, range 34–61). The average age of women at the time of breast cancer diagnosis was 43 years (*SD* = 6.74, range 33–55 years), and the average amount of time that had lapsed since the last active treatment (e.g., surgery, chemotherapy, or radiation) was 23.64 months (*SD* = 22.5 months, range 0.25–6 years). All couples were married and had been in a relationship for an average of 19.68 years (*SD* = 9.6, range = 7.5–44).

Table 1

Demographic and Medical Characteristics (N =28)

Variable	*n*	%
Ethnicity		
White/Caucasian	21	75
Asian/Pacific Islander	3	10.71
Latino/Hispanic/Mexican-Canadian	2	7.14
West Indian	1	3.57
Mixed race from South Africa	1	3.57
Education		
Secondary	3	10.71
University or college	11	39.29
Graduate or professional degree	14	50
Children – couples (*n* =14)		

Yes	11	78.57
No	3	21.43
Medical characteristics - women only (n = 14)		
Stage of cancer		
Stage 0	4	28.57
Stage I	6	42.86
Stage II	1	7.24
Stage III	3	21.43
Treatment		
Lumpectomy alone	2	14.28
Unilateral mastectomy	9	64.29
Bilateral mastectomy	3	21.43
Reconstruction	6	42.86
Chemotherapy	10	71.43
Radiation	9	64.29
Hormonal Therapy	5	35.71
Herceptin Therapy	2	14.28

Recruitment

Participants were recruited over the course of three years through Sunnybrook Odette Cancer Centre (OCC) in collaboration with the SHARE Sexual Health and Rehabilitation and Louise Temerity Breast Centre, and through breast cancer organizations across Ontario. Avenues for recruitment included (1) flyers posted at OCC and community-based

organizations frequented by women with breast cancer; (2) electronic brochures posted on websites commonly accessed by women with breast cancer; and (3) direct referrals by health care providers. In order to facilitate the provision of direct referrals, the study was actively promoted by presenting at numerous interdisciplinary rounds across OCC including Clinical and Academic Supportive Care Rounds, Oncology Grand Rounds, Patient and Family Support Clinical Rounds, Breast Site Group Rounds, and Sexual Health Interprofessional Network meetings. Recruitment at PMH was limited to passive-recruitment by posting flyers at PMH Survivorship Centre and relying on self-referrals.

Participants self-referred by contacting the study coordinator (K. Cullen) via email. Women who were identified by health care professionals as having endorsed sexual difficulties following treatment for breast cancer were provided with information about the study; those who were interested in hearing more about the study gave permission to be contacted directly by the research coordinator. Couples who had previously completed *Couplelinks*, an online intervention supporting young couples' adjustment to breast cancer (Fergus, McLeod, Carter, Warner, Granek, & Cullen, 2014) were also invited to participate by the *Couplelinks* study coordinator, and those who were interested were connected with the study coordinator of the current program via email.

Women expressing interest in the study were contacted by telephone and provided with detailed information about the nature of the study. The study objectives and procedures were discussed, and prospective participants were given the opportunity to ask questions. Women and their partners were also taken through a brief screening interview to determine eligibility (refer to appendix A for screening interview protocol). Couples who met inclusion criteria and agreed to participate were guided through the informed consent process. Participants received

consent forms through the mail or via email, and were asked to return the signed consent forms to Patient and Family Support at the OCC. All couples were provided with the option of receiving a self-addressed, stamped envelope with which to return it.

Once enrolled in the study, each couple completed a psychosexual counseling program consisting of six individual sessions (versus a group program) delivered via eTherapy. Following each session, the facilitator sent couples an email with a brief session summary, highlights regarding the couple's personal experience with the session (e.g., facilitator commenting on a uniting theme that emerged from session), validation of any difficulties, as well as homework for each session.

Measures

Baseline measures.

Demographic and clinical data.

Basic demographic and clinical information were obtained through self-report questionnaires as part of the baseline measure (T0). Participants also had the opportunity to elaborate on their sexual difficulties and goals for the program using open-ended questions.

Breast Cancer Prevention Trial (BCPT) Symptom Checklist.

The BCPT Symptom Checklist is an 18-item shortened version of the 42-item, self-report questionnaire designed to assess the physical effects of breast cancer treatment (Alfazo et al., 2006; Ganz, Day, Ware Redmond, & Fisher,1995; Stanton, Bernaards, & Ganz, 2005). In the BCPT Symptom Checklist, women are asked to rate the extent to which they were bothered by a list of physical symptoms in the past 4 weeks using a 5-point Likert sale ranging from 0 (not at all) to 4 (extremely). The 18 items are summed to create a total score ranging from 0 to 72, with higher scores representing the presence of greater symptomology.

The BCPT Symptom Checklist was found to have good internal consistency (Cronbach's α = .81), and is considered to be an appropriate measure for assessing the presence and severity of physical disturbances in breast cancer patients (Stanton et al., 2005). This questionnaire was administered only to female participants in this study.

Program expectancy questionnaire.

The Credibility and Expectancy Questionnaire (CEQ) is a 6-item, self-report questionnaire whereby participants rate how beneficial they believe the intervention will be and how reasonable it is that this intervention will address their difficulties (Devilly & Borkovec, 2000). This widely used questionnaire evaluates participants' expectations in two parts, with one part asking participants to answer the question based on their rational thought process, and one part asking participants to answer based on their emotions. The original measure was designed to assess predicted amelioration of trauma related symptoms, and the wording was changed in this study to reflect sexual problems. The Program Expectancy Questionnaire was found to have high internal consistency, with Cronbach's α ranging from .81 to .86 across three studies, along with good test-retest reliability (Devilly & Borkovec, 2000).

For the purposes of this study, outcome expectations were assessed at baseline (T0) using a single item asking how much participants expect their sexual intimacy to improve by the end of treatment based on an 11-point Likert Scale ranging from 0 (0%) to 10 (100%). This decision was based on Borkev, Newman, Pincus, and Lytle's (2002) adapted scoring strategy as well as previous outcome studies that have used a single item to assess outcome expectancy and found this to be predictive of treatment outcomes (Ahmed, Westra, & Constantino, 2012; Price, Anderson, Henrich, & Rothbaum, 2008; Vogel, Hansen, Stiles, &

Gotestam, 2006).

Acceptability and feasibility.

Recruitment, retention, and program adherence.

Recruitment was assessed by the number of individuals screened for eligibility versus the number of couples ultimately enrolled in the study. Retention was assessed by the number of couples who completed the intervention. Protocol adherence was assessed by session attendance and homework adherence. Acceptability was assessed by measuring participants' ratings of satisfaction and convenience, along with a qualitative evaluation of participants' overall experience in the program.

Outcome measures.

Outcome measures were selected in accordance with the aims of this study, and guided by outcome measures and protocols of previous studies regarding sexual health outcomes in cancer survivors, psycho-oncology interventions, and pilot studies.

Standardized questionnaires were used to obtain a preliminary estimate of the effectiveness of the program on improving sexual functioning and satisfaction, marital quality, and psychological functioning. The measures used in this study were selected to accurately capture variables of interest while minimizing questionnaire burden. Participants completed self-report questionnaires at three time points: baseline, post-intervention and at 3-month follow-up. See Appendix C for outcome measures. Baseline questionnaires (T0) were completed within one week prior to starting the intervention. Couples were provided with a post-treatment (T1) questionnaire package immediately following completion of the intervention and asked to return within one week. In order to evaluate potential long-term benefits of the intervention, participants were provided with a questionnaire package three

months following completion of the intervention (T2) and asked to return within one week.

Sexual Function Questionnaire (SFQ) for men and women.

The SFQ is a 30-item, self-report questionnaire that was designed to assess various aspects of male and female sexual functioning and satisfaction (Syrjala et al., 2000). The SFQ was originally designed to evaluate sexual functioning in cancer survivors, but has been validated for use with other medical populations and matched controls in the general population. One of the advantages of the SFQ is that it places less emphasis on penetrative sex and/or physiological components of sexual functioning, providing a more nuanced evaluation of sexual domains relevant to this study including activity, interest, desire, arousal, orgasm, satisfaction, and activity. In the SFQ, individuals are asked to rate how frequently they have felt interest or desire, become aroused by, or engaged in specific activities (fantasy to intercourse) in the last month according to a 7-point Likert scale ranging from 0 (not at all) to 6 (more than once a day). Relationship and other satisfaction items are rated according to a 6-point Likert scale ranging from 0 (very dissatisfied) to 5 (very satisfied) or 11-point Likert scale ranging from 0 (not at all) to 10 (extremely). In addition to an overall SFQ score and SFQ subscale scores, the SFQ also includes a Cancer Impact subscale to assess the perceived impact of cancer on the sexual relationship according to a 6-point Likert scale, ranging from 1 (not at all) to 6 (all the time). A more detailed description of each subscale can be found in Appendix E. For overall score and each subscale score, a higher number means better sexual functioning. The only exception includes the Cancer Impact subscale, such that lower scores denote an improvement on the perceived impact that breast cancer has had on the couple's sexual relationship.

The overall SFQ and SFQ subscales have strong internal reliability (Cronbach's α

ranging from .81 to .93), for men, women, cancer populations, and control populations, and has adequate test-retest reliability. Criterion validity was demonstrated through high correlation of the SFQ relationship subscale and the Dyadic Adjustment Scale, a widely used self-report scale assessing the quality of relationship adjustment in couples (Spainer, 1976). Discriminant validity was demonstrated by significantly higher SFQ scores in individuals that were sexually active in the past month versus those that were not (Syrjala et al., 2000). The SFQ has been used to assess sexual functioning in various health populations and in studies evaluating the impact of interventions designed to improve sexual and relationship functioning in cancer populations (Brotto et al., 2008; Brotto et al., 2012; Hampton, Walker, Beck & Robinson, 2013; Walker, King, Kwansy, & Robinson, 2017; Wittmann & Koontz, 2017).

Revised Dyadic Adjustment Scale (R-DAS).

The R-DAS is a 14-item, self-report questionnaire designed to assess quality of adjustment in couples' relationships (Busby, Crane, Larson & Christensen, 1995). Subscales include dyadic consensus, dyadic satisfaction, and dyadic cohesion, with an overall score of dyadic adjustment measured as the sum of these three subscales. In the R-DAS, individuals are asked to rate the extent to which they agree or disagree with their partner on various matters (e.g., religion, finances), or the frequency to which certain events occur in their relationship (e.g., quarrel, engage in stimulating conversations) using a 6-point Likert scale ranging from 0 (never/always disagree) to 5 (all the time/always agree). The 14 items are summed to create a total score ranging from 0 to 69, with higher scores indicating more positive dyadic adjustment (Crane, Middleton, & Bean, 2000).

The overall R-DAS and R-DAS subscales have strong internal reliability (Cronbach's α ranging from .81 to .90). The R-DAS was also found to have good construct and criterion

validity (Busby, et al., 1995). The R-DAS is widely used by researchers and practitioners to assess martial satisfaction (Ward, Lundberg, Zabriskie, & Berrett, 2009), and in studies evaluating the impact of interventions designed to improve martial quality in couples affected by cancer (Fergus et al. 2015; McLean et al., 2008; Rowland et al., 2009).

Maudsley Marital Questionnaire (MMQ).

The MMQ is a 20-item, self-report questionnaire designed to assess marital/relationship adjustment or happiness using three subscales: marital quality, sexual quality, and general life. For the current study, only the 10-item marital quality subscale was administered. Marital quality was assessed using 10 items, whereby participants were asked to provide a response that best reflects the status of their relationship. All items are rated using a 9-point Likert scale with different labels for each item. Scores range from 0 to 80, with higher scores representing greater adjustment problems and/or poorer marital quality (Arrindell, Boelens, & Lambert, 1983; Orathinkal, Vansteenwegen, & Stroobants, 2007).

The Martial Quality (MQ) subscale possesses both concurrent and discriminant construct validity. The Cronbach α for the MQ subscale has been found to range between .85 and .90, demonstrating reliability for this subscale (Arrindell, Boelens, & Lambert, 1983; Orathinkal, Vansteenwegen, & Stroobants, 2007). The MMQ is commonly used to evaluate martial quality in chronic illness populations as well as physically healthy couples, and in studies evaluating the impact of couples and sexual counselling interventions, including couples affected by cancer (Barbato & D'Avanzo, 2008; Yasan & Gürgen, 2008; Tuinman, Fleer, Sleijfer, Hoekstra, & Hoekstra-Weebers, 2005).

Centre for Epidemiological Studies Depression Scale (CES-D).

The CES-D is a 20-item, self-report questionnaire originally designed to assess

depressive symptomology in the general population (Radloff, 1977). In the CES-D, individuals are asked to rate the extent to which they experienced depressive symptoms within the last week using a 4-point Likert sale ranging from 0 (rarely or none of the time/less than 1 day) to 3 (most or all of the time/5-7 days). Scores range from 0 to 60, with higher scores representing the presence of greater symptomology.

The CES-D was established as a valid and reliable measure of depression in general and medical populations, including cancer patients, with high internal consistency (Cronbach's $\alpha = .85$), good construct validity, and adequate test-retest reliability (Hann, Winter, & Jacobsen, 1999; Radloff, 1977). In addition to being a commonly used tool for assessing depressive symptomology, the CES-D has been used in intervention studies for breast cancer survivors and their partners/caregivers, along with couples-based interventions (Jones et al., 2013; Kalaitzi et al., 2007)

Generalized Anxiety Disorder Assessment (GAD-7).

The GAD-7 is a 7-item, self-report screening measure for Generalized Anxiety Disorder (Spitzer, Kroenke, Williams, & Löwe, 2006). In the GAD-7, individuals are asked to rate the extent to which they are bothered by a list of symptoms in the past 2 weeks using a 4-point Likert sale ranging from 0 (not at all) to 3 (nearly every day). Scores range from 0 to 21, with higher scores representing the presence of greater symptomology.

The GAD-7 was found to have high internal consistency (Cronbach's $\alpha = .91$) good reliability, along with good criterion, construct, factorial, and procedural validity (Spitzer et al, 2006; Delgadillo et al., 2012). The GAD-7 is an efficient screening tool for anxiety symptoms in clinical practice and in research, both in general psychiatric populations and in cancer patients (Anderson et al., 2014; Kroenke et al., 2010; Mehnert et al., 2012; Spitzer et al, 2006).

Program satisfaction and convenience.

Participants were asked to complete a brief satisfaction questionnaire at T1. All participants were asked to rate their satisfaction with the intervention, along with the degree to which they agreed that the program was convenient using a 5-point Likert scale ranging from 1 (very dissatisfied/strongly disagree) to 5 (very satisfied/strongly agree). Participants were also provided with the opportunity to elaborate on their responses through open ended questions.

Qualitative feedback.

Qualitative feedback was collected to provide information regarding program acceptability, gain a more in-depth understanding of couples' experiences, and obtain feedback on how the intervention could be improved and refined.

In addition to answering open-ended questions regarding their satisfaction and experience with the intervention in the post-treatment questionnaire (T1), couples participated in a post-treatment interview delivered via telephone or using VSee. Following completion of the program, couples were invited to participate in a post-treatment interview, and those who agreed were contacted by a research assistant. Participants were interviewed as a couple (rather than separately), and all interviews were conducted by trained research assistants or graduate students in the Psychosocial Oncology Lab at York University who were not involved in the delivery or evaluation of the intervention. Interviews were semi-structured, consisting of open-ended questions regarding couples' overall experience, program expectations, helpful versus less helpful components, likes and dislikes, and attitudes towards the homework, program facilitator, and online delivery, as well as suggested modifications. Interviews were digitally recorded, transcribed, and analyzed using ualitative content analytic methods (described in a later section of this paper). Please see Appendix F for post-treatment interview

protocol.

Analysis

Feasibility and acceptability.

Participant recruitment, retention, and treatment adherence were monitored as indicators of acceptability and feasibility. Participants' subjective experiences in completing the interventions were also explored.

Quantitative analysis.

Multilevel Modeling (MLM) is recommended for the analysis of dyadic data (Atkins, 2005; Kenny, Kashy, Cook, & Simpson, 2006), and is increasingly being recommended as an alternative to traditional statistical models in research involving couples and/or families (Kwok, Underhill, Berry, Luo, Elliot, & Yoon, 2008). The growing recognition of the importance of incorporating both partners' perspectives when examining sexual and reproductive health behaviours (Preciado, Krull, Hicks, & Gipson, 2016), provides further rationale for the suitability of MLM for this study.

MLM is based on the premise that individuals nested within a group (in this case an individual nested within a couple or dyad) tend to be more similar to one another than to other individuals, and includes error terms that account for nonindependence of observations that may cause problems in classical statistical methods (Atkins, 2005). For instance, whereas standard regression includes a single error term, MLM includes multiple error terms. Thus, when nested data are analysed using traditional methods, Type 1 error rates tend to be inaccurate due to nonindependence of observations (Kenny et al., 2006). In MLM, nonindependence of observations is adequately captured by explicitly modeling within- and

between-group variability with the inclusion of error terms at each level of the model (Atkins, 2005).

In addition to accounting for nested data by estimating the variance at every level of the hierarchy in which the data are nested, MLM provides several advantages over the use of classical models in the analysis of longitudinal data. A major advantage of MLM is that missing data can be handled more flexibly, such that MLM does not require complete data on all participants (Atkins, 2005; Kwok et al., 2008). Accordingly, MLM makes use of all available data in the estimation of model parameters, and participants with missing data at any timepoint can still be included in the analysis (Kwok et al., 2008). This was particularly advantageous in the current study as some participants did not complete self-report measures at T2 (3-month follow-up), with one participant not completing the T1 (post-treatment) measures. An additional advantage is that MLM does not require participants to be assessed at the same time, and observations can be collected at unequally spaced intervals (e.g., 0 months, 1 month, 6 months) (Kwok et al., 2008). In the current study, data were collected at baseline, post-intervention (6 weeks), and at 3-month follow-up. The treatment of time as a continuous variable also has the potential to increase statistical power for detecting change (Muthén & Curran, 1997). The ability to analyze dyadic data, along with the flexibility with respect to its treatment of time and missing data, made MLM the most appropriate statistical approach for this study.

Data analysis.

Data analysis was conducted using IBM SPSS Statistics software. Self-report data were analyzed using MLM and Bonferroni pairwise comparisons to examine the effect of the intervention on sexual and dyadic functioning. Of particular interest was whether this

intervention would lead to improvements in sexual and dyadic functioning (T0 versus T1), and whether these improvements would be sustained over time (T0 versus T2).

As recommended by Atkins (2005) and other researchers (Kenny et al., 2006), a three-level model with time (level 1), nested within individuals (level 2), nested within couples (level 3) was applied to examine change in scores over time, with gender included as a predictor variable. Given that length of relationship can play a role in couples' dyadic adjustment to breast cancer (Badr, Carmack, Kashy, Cristofanilli, & Revenson, 2010), and that physical symptoms (e.g., hot flashes, vaginal pain/discomfort, general pain, fatigue, etc.) associated with breast cancer treatment can affect women's sexual functioning and relationships (Ganz, Desmond, Belin, Meyerowitz, & Rowland, 1999; Graziottin, 2008), it was important to take these two constructs into account when conducting the analysis. Accordingly, in order to conduct a stringent test of the effectiveness of the psychosexual intervention, the length of relationship, as well as women's breast cancer-related physical symptoms (as measured by their baseline BCPT symptom checklist scores) were included as covariates in the model. Regression models were estimated by the restricted maximum likelihood procedure (REML). A comparison of baseline (T0) scores to post-test (T1) and 3-month follow-up (T2) were of particular interest to the research question, and Bonferonni corrections were used to adjust alpha levels to account for the multiple analyses. Post-test and follow-up effect sizes (Cohen's d) were computed to determine the magnitude of change.

Qualitative analysis.

Qualitative analysis of participants' written survey data and post-treatment interviews was guided by the qualitative content analysis approach outlined in Graneheim & Lundman (2014) in order to describe couples' experiences in completing the intervention as it pertained

to the primary aims of this study. Qualitative content analysis can be defined as a scientific study of qualitative data that utilizes systematic and rule-based techniques to objectively describe, code, and categorize data (Forman & Damschroder, 2007). Qualitative content analysis is a widely used qualitative research technique, and is particularly prominent in nursing research, as well as in the medical and bioethics literature (Forman & Damschroder, 2007).

The purpose of qualitative content analysis is to generate knowledge and extract categories from the data, as opposed to interpreting meaning and/or developing a theory about a particular phenomenon. In line with the primary objectives of this study (i.e., evaluation of the intervention's feasibility and acceptability and its impact on couples' sexual relationship) a descriptive (versus interpretive) approach was considered to be more appropriate to this analysis because it allows us to objectively capture and describe participants' experiences of receiving the intervention. Accordingly, the analysis was focused on the manifest (descriptive, visible surface-level) versus latent (deeper underlying meaning of the text based on a higher level of inference) content vis-à-vis the data (Graneheim & Lundman, 2014).

NVivo 10 qualitative analysis software was used to assist with the organization and analysis of the text data. Participant surveys, along with transcripts of post-treatment interviews were read through several times to obtain a sense of the data as a whole. Particular areas of interest included: 1) positive and negative aspects; 2) areas for modification and improvement; 3) acceptability and utility of online delivery; and 4) treatment outcomes - including the degree to which the intervention addressed couples' difficulties with their sexual relationship. Next, all text relevant to the areas described above was identified and divided into specific units of analysis known as "meaning units" (Giorgi, 1970) or "content units"

(Baxter, 1991). A meaning unit is a segment of text that represents a discrete idea, thought, issue, observation, or process being described by a participant (Angus & Rennie, 1989). Each meaning unit was condensed into a phrase or word that best articulated the concept being expressed, and subsequently labelled with a code. Codes that shared a commonality were then grouped in to sub-themes. As emphasized by Krippendorff (1980), sub-themes were exhaustive, and no data related to the study aims were excluded due to lack of suitability. As the analysis progressed, sub-themes were sometimes re-titled to explain or better articulate the description inherent in a particular grouping of codes. Consistent with the descriptive nature of this analysis, theme names closely reflected the language used by participants. In the later stages of analysis, the sub-themes were examined for relationships and sorted so that lower order categories with shared content/meaning were grouped together to form main themes.

Triangulation.

Triangulation is broadly defined as the combined use of multiple methods and data sources to examine and understand a common phenomenon (Jick, 1979). The purpose of triangulating multiple data sources in this study was twofold. First, it enhanced the likelihood of obtaining trustworthy findings by facilitating validation of data through cross-verification of multiple data sources (Bogdan & Biklen, 2006; Lincoln & Guba 1985). Second, it provided more nuanced information with respect to the intervention's feasibility and acceptability than would be achieved by examining qualitative or quantitative data alone. Correspondingly, this study was strengthened not simply by integrating quantitative *and* qualitative data, but by integrating multiple data sources including self-report measures, open-ended questions that allowed participants to elaborate on their experience and satisfaction with the program, and post-treatment interviews.

Chapter 3: Results

Feasibility and Acceptability

Recruitment and retention.

Of the 38 women and/or couples who expressed interest in learning more about the study through initial email contact and/or were screened for eligibility, seven declined participation, seven did not meet criteria, and six never followed through. The reasons provided by those who declined participation were that they were too busy (n = 3), did not require assistance with their sexual/intimate relationship and/or did not feel as though the program would be a good fit (n = 2), or that the woman's partner declined to participate (n = 2). Reasons for exclusion included a diagnosis of metastatic breast cancer (n = 3), diagnosed with breast cancer over 6 years ago (n = 1), high levels of martial distress[2] (n = 1), and absence of notable changes to their sexual relationship due to breast cancer (n = 2). Two couples who were enrolled in the study never officially began the intervention, and one couple did not complete the program. Of the two non-starters, one couple withdrew because they were unable to coordinate their schedules, and one couple did not respond to follow-up emails. The couple that did not complete the program cancelled several sessions and did not respond to follow-up emails and rescheduling attempts. A fourth couple was deemed to be ineligible after it became evident during the first session that their sexual problems were related to marital difficulties that predated cancer, and that the couple was seriously considering divorce. Specifically, during the first session (which involves a more in-depth clinical interview), the couple revealed that they were motivated to pursue this intervention because their previous experience with marital therapy had not been successful and they wanted to explore additional therapy prior to

[2] At the time of initial phone contact, the female partner revealed that her relationship issues were primarily related to infidelity and pornography addiction.

making a decision about ending their marriage. For ethical reasons, the couple was permitted to complete the intervention, but were ultimately excluded from the study. In summary, a total of 18 couples were enrolled in the study, with 15 completing the program, but only 14 couples whose data formed the basis for this analysis.

Program adherence.

Fourteen out of fifteen couples who commenced the interventions completed all six session. The fourteenth couple completed four sessions. Sessions were delivered on a weekly basis, although there was some variation in this schedule as a result of couples cancelling or rescheduling appointments, as well as pre-determined absences. On average, couples completed the 6-session intervention in 10.07 weeks (range 7–13 weeks). Five couples also required an additional session during the intervention to address challenges with homework scheduling.

Program satisfaction and convenience.

Twelve out of fourteen couples completed the post-treatment satisfaction questionnaire.[3] The mean global satisfaction for participants who completed the post-treatment satisfaction measures (n = 24) was 4.58 out of 5 (SD = 0.58), whereby 95% of participants indicated that they 'strongly agreed' (n = 15) or 'agreed' (n = 8) that they were satisfied with the program. Only one participant (C009M) indicated that he "neither agreed nor disagreed." Program convenience was rated 4.63 on average out of 5 (SD = 0.58), with 95% of participants strongly agreeing (n = 16) or agreeing (n = 7) with a statement that the program was convenient. Only one participant (C008M) indicated that he "neither agreed nor disagreed."

[3] When couples C001 and C004 completed the intervention, the satisfaction survey had not yet been included in the post-treatment questionnaire. Although both couples were sent the satisfaction surveys after it was developed, neither returned the survey and did not respond to follow-up requests.

Preliminary Evaluation of Effectiveness

Preparation of data.

Exploratory analyses were conducted to evaluate outliers and assumptions of normality and homogeneity for the entire sample, as well as separately for males and females. Results of Levene's tests were all found to be non-significant, suggesting that the variance of scores were normally distributed for the entire sample, as well as for males and females. Values of skew and kurtosis for total and subscale scores at each time point were converted to z-scores. For the entire sample, at T0 (baseline), all data were within normal limits (< |1.96| at $p < .05$) except for SFQ-orgasm (significant skew). At T1 (post-treatment), all data were within normal limits (< |1.96| at $p < .05$) except for SFQ Total (significant skew), SFQ-satisfaction (significant skew and kurtosis), SFQ-problems (significant skew), and SFQ-orgasm (significant skew and kurtosis). At T2 (3-month follow-up), all data were within normal limits (< |1.96| at $p < .05$) except for SFQ-interest (significant skew), SFQ-satisfaction (significant skew), SFQ-problems (significant skew), and SFQ-orgasm (significant skew). For females, at T0, all data were within normal limits (< |1.96| at $p < .05$) except for SFQ interest (significant skew and kurtosis) and SFQ-masturbation (significant skew). At T1, all data were within normal limits (< |1.96| at $p < .05$) except for SFQ-interest (significant skew), SFQ-masturbation (significant skew), SFQ-orgasm (significant skew), MMQ-martial quality (significant skew), and GAD-7 (significant skew). At T2, all data were within normal limits (< |1.96| at $p < .05$) except for SFQ-interest (significant skew), MMQ-martial quality (significant skew), and CES-D (significant skew). For males, at T0, all data were within normal limits (< |1.96| at $p < .05$) except for SFQ-problems (significant skew) and SFQ-orgasm (significant skew). At T1, all data were within normal limits (< |1.96| at $p < .05$) except for SFQ-satisfaction (significant

skew) and SFQ-problems (significant skew). At T2, all data were within normal limits (< |1.96| at $p < .05$) except for SFQ-desire (significant skew and kurtosis) and SFQ-satisfaction (significant skew and kurtosis).

Visual examination of histograms and boxplots suggested that skew and/or kurtosis was attributed primarily to the presence of outliers. Subsequently, regression diagnostics were used to assess the influence of outliers on the model. Cook's distance (D_i) is a measure of the influence of each data point with values $Di > 1$ indicating that the data point strongly influences the fitted values (Cook, 1977). Cook's distance measures, along with a visual inspection of regression distributions, found that no data points were considered to be influential. Moreover, because deviations from normality are more likely to occur in small samples, no transformations were completed.

Treatment results.

After controlling for the length of relationship and symptom severity (BCPT symptom checklist scores)[4], MLM revealed a significant effect of time for SFQ Total $F(2, 43.65) = 5.26$, $p = .009$, SFQ-arousal $F(2,43.25) = 5.46$, $p = .008$, and for SFQ-activity $F(2,42.7) = 6.77$, $p = .003$.

Descriptive statistics for all variables across time are presented in Table 2. Effect sizes for pairwise comparisons are presented in Table 5. Bonferroni adjusted pairwise comparisons revealed significant improvements from T0 to T1 for SFQ Total $t(39.71) = 5.39$, $p < .001$, SFQ-arousal $t(39.17) = 5.87$, $p < .001$, SFQ-satisfaction $t(38.72) = 3.83$, $p = .001$, SFQ-problems, $t(41.996) = 4.68$, $p < .001$, SFQ-activity $t(37.64) = 4.30$, $p < .001$, SFQ-relationship $t(41.59) = 4.88$, $p < .001$, SFQ-cancer impact $t(41.17) = 5.22$, $p < .001$, R-DAS $t(42.51) = 3.44$,

[4] The average symptom severity for women (as assessed using the BCPT symptom checklist) was 29.19 (SD = 11.2, range 6-51).

p = .004, and CES-D $t(42.51) = 3.44$, p = .004. There were large effect sizes for SFQ-arousal and SFQ-relationship, and moderate effect sizes for SFQ Total, SFQ-satisfaction, SFQ-activity, and SFQ-impact. Bonferroni adjusted pairwise comparisons revealed a significant difference from T0 to T2 for SFQ-problems $t(45.84) = 3.75$, p =.002, SFQ-relationship $t(62.46) = 3.10$, p = .009, and SFQ-cancer impact $t(54.81) = 4.10$, $p < .001$. There were large effect sizes for SFQ-relationship, and moderate effect sizes for SFQ-satisfaction, SFQ-activity, and SFQ-impact. The effect of SFQ-arousal was not maintained at T2. There were also no significant effects for marital quality (MMQ) or dyadic adjustment (R-DAS) from T0 to T1 or from T0 to T2.

Table 2.

Mean Values of Outcome Variables Across Time for Entire Sample (N = 28)

Measure	Baseline (T0) *M (SD)*	Post-treatment (T1) *M (SD)*	Three-month follow-up (T2) *M (SD)*
SFQ Total	2.47 (0.84)	2.94 (.96)**	2.7 (0.84)
SFQ-interest	1.89 (1.75)	2.06 (1.76)	1.46 (1.70)
SFQ-desire	3.29 (1.15)	3.43 (1.10)	3.31 (1.19)
SFQ-arousal	1.64 (1.33)	2.77 (1.16)**	2.17 (1.32)
SFQ-satisfaction	2.67 (1.33)	3.64 (1.35)**	3.40 (1.25)
SFQ-problems	3.35 (1.58)	3.77 (1.38)**	3.85 (1.30)*
SFQ-activity	1.41 (1.31)	2.32 (1.12)**	1.97 (0.94)
SFQ-masturbation	1.86 (1.74)	1.76 (1.73)	1.75 (1.67)
SFQ-orgasm	3.19 (1.55)	3.67 (1.26)	3.43 (1.39)
SFQ-relationship	2.30 (0.95)	3.46 (1.25)**	3.25 (1.15)*
SFQ-cancer impact	3.01 (0.87)	2.48 (0.83)**	2.32 (0.95)**
MMQ-marital quality	16.97 (9.09)	13.48 (9.48)	12.21 (9.29)
R-DAS	48.45 (6.48)	50.81 (6.34)*	51.04 (5.11)
CES-D	13.20 (7.48)	10.22 (8.46)*	11.08 (7.73)
GAD-7	5.98 (5.24)	4.59 (4.57)	4.88 (4.19)

Note. * Pairwise comparison significantly different from T0 at $p < .01$; **Pairwise comparison significantly different from T0 at $p < .001$. SFQ = Sexual Functioning Questionnaire; MMQ = Maudsley Marital Questionnaire; R-DAS = Revised Dyadic Adjustment Scale; CES-D = Centre for Epidemiological Studies Depression Scale; GAD-7 = Generalized Anxiety Disorder Assessment. An increase in SFQ (including SFQ-problems) and R-DAS denotes an improvement for these constructs. A decrease in SFQ-cancer impact, MMQ-martial quality, CES-D, and GAD-7 denotes an improvement in these constructs.

Due to prospective gender differences in sexual and/or relational experiences (Birnbaum, & Laser-Brandt, 2002; Hook, Gerstein, Detterich, & Gridley, 2003), along with the patient status of female participants in this study, it was anticipated that males and females would differ in their response styles to self-report measures. Visual examination of outcome variable trajectories for males and females provided evidence in support of this, particularly with respect to sexual functioning (see Figures 2-12). MLM confirmed this hypothesis and yielded a main effect for gender on SFQ Total, $F(1, 25.71) = 28.10$, $p < .001$, SFQ-interest $F(1, 24.85) = 20.85$, $p < .001$, SFQ-desire $F(1, 23.69) = 20.92$, $p < .001$, SFQ-arousal $F(1, 24.34) = 8.89$, $p = .006$, SFQ-satisfaction $F(1, 24.51) = 6.92$, $p = .015$, SFQ-problems $F(1, 24.48) = 28.31$, $p < .001$, SFQ-masturbation $F(1, 24.04) = 8.84$, $p = .007$, and SFQ-cancer impact $F(1, 24.21 = 21.50)$, $p < .001$. Given that significant gender differences were found for the vast majority of SFQ measures, separate analyses for males and females were conducted for all SFQ subscales.

For females ($n = 14$), MLM revealed a significant effect of time for SFQ-arousal $F(2, 19.78) = 4.56$, $p = .024$, SFQ-activity $F(2, 19.92) = 6.72$, $p = .006$, and SFQ-cancer impact $F(2, 19.64) = 5.82$, $p = .01$. Descriptive statistics for all variables across time are presented in Table 3. Effect sizes for pairwise comparisons are presented in Table 5. Bonferroni pairwise comparisons revealed significant improvements from T0 to T1 for SFQ Total $t(18.99) = 3.67$, $p = .005$, SFQ-arousal $t(18.60) = 5.12$, $p <.001$, SFQ-problems $t(18.18) = 4.01$, $p = .002$, SFQ-activity $t(18.58) = 3.72$, $p = .005$, SFQ-relationship $t(18.47) = 3.34$, $p = .011$, and SFQ-cancer impact $t(18.98) = 5.66$, $p < .001$. There were large effect sizes for SFQ-arousal, SFQ-relationship, and SFQ-cancer impact, and moderate effect sizes for SFQ-satisfaction and SFQ-activity. Bonferroni adjusted pairwise comparisons also revealed a significant difference from

T0 to T2 for SFQ-problems $t(19.86) = 3.37$, $p = .009$ and SFQ-cancer impact $t(22.94) = 3.58$, $p = .005$. There were large effect sizes for SFQ-cancer impact and moderate effect sizes for SFQ-satisfaction, SFQ-activity, SFQ-orgasm, and SFQ-relationship. The effect of SFQ-arousal was not maintained at T2. There were no significant effects for marital quality (MMQ) or dyadic adjustment (R-DAS) from T0 to T1 or from T0 to T2.

Table 3.

Mean Values for Sexual Functioning Variables Across Time for Females (n = 14)

Measure	Baseline (T0) *M (SD)*	Post-treatment (T1) *M (SD)*	3-month (T2) follow-up *M (SD)*
SFQ Total	1.89 (.67)	2.40 (0.95)**	2.18 (0.71)
SFQ-interest	0.79 (1.12)	1.17 (1.58)	0.41 (0.80)
SFQ-desire	2.64 (0.86)	2.83 (0.97)	2.55 (0.87)
SFQ-arousal	1.16 (1.08)	2.31 (1.08)***	1.55 (1.10)
SFQ-satisfaction	2.27 (1.34)	3.04 (1.59)	3.09 (1.34)
SFQ-problems	2.24 (1.41)	2.85 (1.40)**	2.89 (1.37)**
SFQ-activity	1.21 (1.20)	2.11 (1.16)	1.91 (1.04)
SFQ-masturbation	0.96 (1.20)	1.11 (1.64)	0.77 (0.96)
SFQ-orgasm	2.79 (1.42)	3.14 (1.46)	3.41 (0.96)
SFQ-relationship	2.07 (1.09)	3.21 (1.42)*	3.05 (1.51)
SFQ-cancer impact	3.62 (0.64)	2.87 (0.89)***	2.77 (1.72)**

Note. * Pairwise comparison significantly different from T0 at $p < .05$; **Pairwise comparison significantly different from T0 at $p < .01$; *** Pairwise comparison significantly different from T0 at $p < .001$. SFQ = Sexual Functioning Questionnaire. An increase in SFQ (including SFQ-problems) denotes an improvement for these constructs. A decrease in SFQ-cancer impact denotes an improvement.

For males (n =14), MLM revealed a significant effect of time for SFQ-satisfaction $F(2, 20.01) = 4.24$, $p = .029$. Descriptive statistics for all variables across time are presented in Table 4. Effect sizes for pairwise comparisons are presented in Table 5. Bonferroni corrected comparisons revealed significant improvements from T0 to T1 for SFQ Total $t(16.69) = 3.69$, p = .006, , SFQ-arousal $t(16.86) = 3.26$, $p = .014$, SFQ-satisfaction $t(14.61) = 3.00$, $p = .027$, , and SFQ-relationship = $t(17.70) = 3.75$, $p = .005$,. There was a large effect size for SFQ Total, SFQ-arousal, SFQ-satisfaction, SFQ-activity, and SFQ-relationship, and moderate effect size for SFQ-orgasm and SFQ-cancer impact. When comparing T0 to T2, there was a large effect size for SFQ-relationship and a moderate effect size for SFQ-satisfaction. The effects of SFQ-Total, SFQ-arousal, SFQ-activity, SFQ-orgasm, and SFQ-cancer impact were not maintained at T2. There were no significant effects for marital quality (MMQ) or dyadic adjustment (R-DAS) from T0 to T1 or from T0 to T2.

Table 4.

Mean Values for Sexual Functioning Variables Across Time for Males (n = 14)

Measure	Baseline *M (SD)*	Post-treatment *M (SD)*	3-month follow-up *M (SD)*
SFQ Total	3.01 (0.56)	3.57 (0.49)**	3.18 (0.65)
SFQ-interest	3.00 (1.56)	3.00 (1.46)	2.35 (1.77)
SFQ-desire	3.95 (1.04)	4.06 (0.86)	3.77 (1.16)
SFQ-arousal	2.12 (1.42)	3.31 (1.04)*	2.69 (1.29)
SFQ-satisfaction	3.07 (1.26)	4.31 (0.55)*	3.65 (1.17)
SFQ-problems	4.46 (0.72)	4.69 (0.40)	4.67 (0.31)
SFQ-activity	1.61 (1.42)	2.58 (1.06)	2.04 (0.86)
SFQ-masturbation	2.75 (1.77)	2.46 (1.59)	2.58 (1.73)
SFQ-orgasm	3.61 (1.61)	4.23 (0.67)	3.46 (1.70)
SFQ-relationship	2.54 (0.75)	3.73 (1.01)**	3.42 (0.76)
SFQ-cancer impact	2.39 (0.58)	2.04 (0.52)	1.94 (0.49)

Note. * Pairwise comparison significantly different from T0 at $p < .05$, **Pairwise comparison significantly different from T0 at $p < .01$. SFQ = Sexual Functioning Questionnaire. An increase in SFQ (including SFQ-problems) denotes an improvement for these constructs. A decrease in SFQ-cancer impact denotes an improvement.

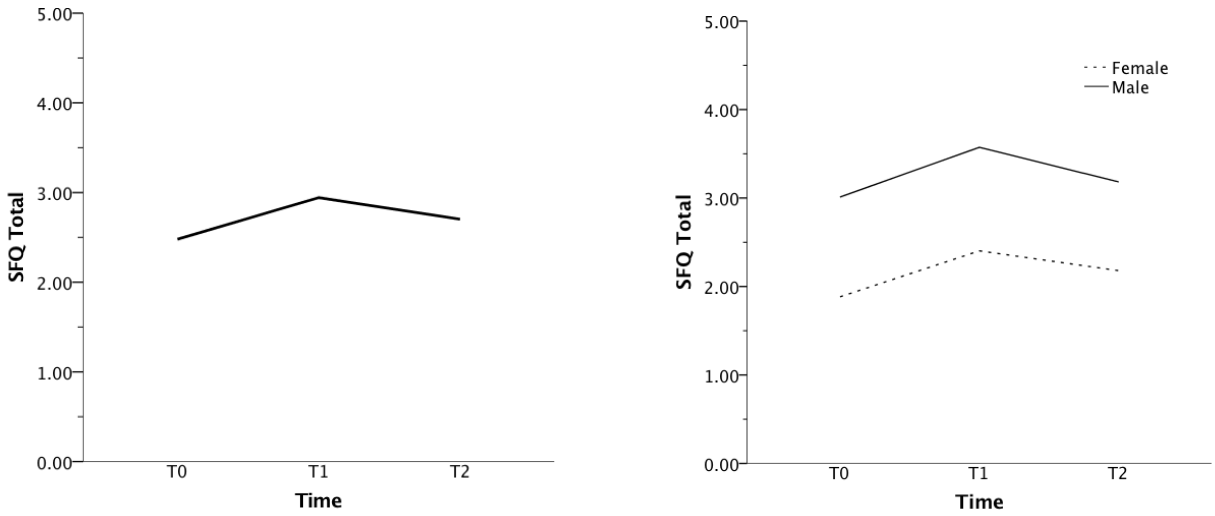
Table 5.

Contrast of Baseline (T0) with Post-Treatment (T1) and 3-Month Follow-up (T2) Scores for Outcome Variables

Variable	All participants (n = 28)		Females (n = 14)		Males (n = 14)	
	T0-T1 *d* [95% CI]	T0-T2 *d* [95% CI]	T0-T1 *d* [95% CI]	T0-T2 *d* [95% CI]	T0-T1 *d* [95% CI]	T0-T2 *d* [95% CI]
SFQ Total	0.54 [0.30, 0.78]	0.29 [0.06, 0.51]	0.65 [0.34, 0.95]	0.44 [0.17, -0.71]	1.11 [0.91, 1.30]	0.30 [0.07, 0.52]
SFQ-interest	0.10 [-0.55, 0.359]	0.26 [-0.20, 0.72]	0.30 (-0.79, 0.19]	0.40 [0.02, 0.77]	0.00 [-0.55, 0.55]	0.41 [-0.20, 1.01]
SFQ-desire	0.12 [-0.41, 0.18]	0.08 [-0.23, 0.39]	0.22 (-0.54, 0.11]	0.12 [-0.21, 0.44]	0.12 [-0.47, 0.23]	0.17 [-0.22, 0.57]
SFQ-arousal	0.92 [0.59, 1.25]	0.40 [0.05, 0.76]	1.10 [0.71, 1.48]	0.36 [-0.77, 0.05]	0.98 [0.51, 1.45]	0.44 [-0.93, 0.06]
SFQ-satisfaction	0.74 [0.39, 1.09]	0.57 [0.22, 0.92]	0.54 (0.02, 1.07]	0.64 [0.14, 1.14]	1.31 [0.95, 1.66]	0.50 [0.06, 0.94]
SFQ-problems	0.29 [-0.67, 0.10]	0.35 [-0.74, 0.04]	0.45 (-0.96, 0.07]	0.48 [-1.01, 0.05]	0.40 [0.19, 0.62]	0.39 [-0.18, 0.59]
SFQ-activity	0.77 [0.45, 1.08]	0.50 [0.19, 0.81]	0.78 (0.36, 1.21]	0.64 [0.21, 1.06]	0.80 [0.33, 1.27]	0.38 [-0.82, 0.06]
SFQ-masturbation	0.06 [-0.39, 0.51]	0.06 [-0.39, 0.52]	0.10 (-0.62, 0.41]	0.18 [-0.23, 0.60]	0.18 [-0.43, 0.79]	0.10 [-0.53, 0.74]
SFQ-orgasm	0.34 [-0.71, 0.03]	0.17 [-0.56, 0.23]	0.26 (-0.77, 0.26]	0.52 [0.05, 0.99]	0.52 [0.07, 0.97]	0.09 [-0.51, 0.69]
SFQ-relationship	1.07 [-1.36, -0.78]	0.92 [-1.20, -0.64]	0.94 (-1.39, -0.48]	0.79 [-1.27, -0.30]	1.41 [1.08, 1.73]	1.23 [0.95, 1.50]
SFQ-cancer impact	0.63 [0.41, 0.86]	0.77 [0.53, 1.01]	1.01 (0.73, 1.29]	0.98 [0.64, 1.32]	0.64 [0.44, 0.84]	0.86 [0.66, 1.06]
MMQ	0.38 [-2.03, 2.79]	0.53 [-1.92, 2.98]	0.60 (-3.37, 4.57]	0.45 [-3.98, 4.88]	0.09 [-2.40, 2.57]	0.78 [-1.20, 2.76]

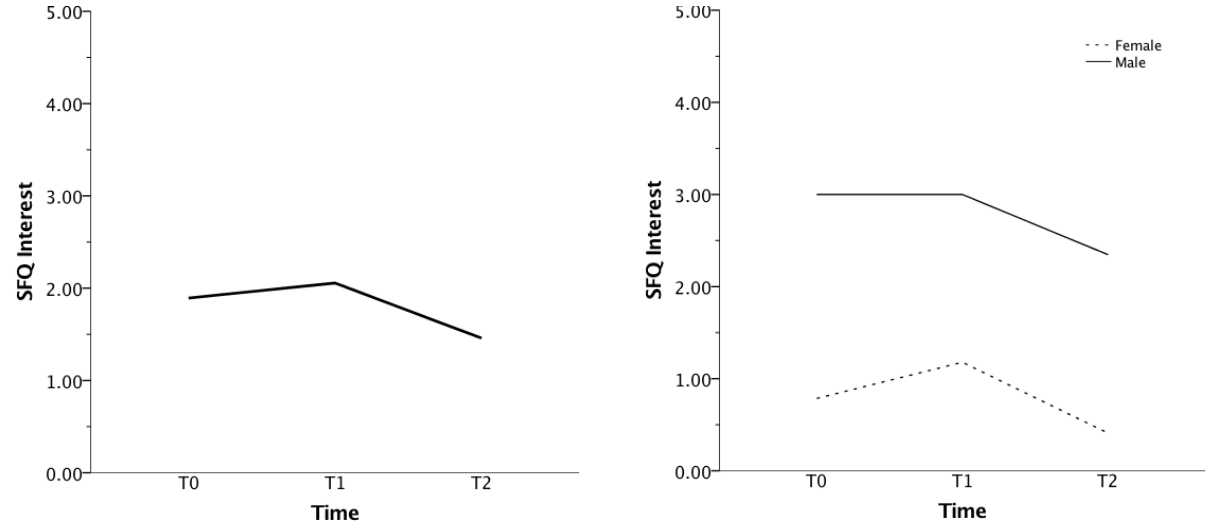
R-DAS	0.38 [-2.04, 1.29]	0.45 [-2.02, 1.12]	0.55 (-3.07, 1.97]	0.56 [-3.04, 1.92]	0.20 [-2.18, 1.79]	0.32 [-2.08, 1.45]
CES-D	0.38 [-1.69, 2.45]	0.28 [-1.72, 2.29]	0.54 (-2.41, 3.49]	0.30 [-2.85, 3.45]	0.22 [-2.64, 3.08]	0.24 [-2.25, 2.73]
GAD-7	0.29 [-0.99, 1.57]	0.24 [-1.03, 1.50]	0.32 (-1.73, 2.38]	0.33 [-1.63, 2.29]	0.28 [-1.14, 1.70]	0.11 [-1.46, 1.68]

Note: *d* = Cohen's d; CI = 95% confidence interval. SFQ = Sexual Functioning Questionnaire; MMQ = Maudsley Marital Questionnaire (marital quality subscale); R-DAS = Revised Dyadic Adjustment Scale; CES-D: Centre for Epidemiological Studies Depression Scale; GAD-7 = Generalized Anxiety Disorder Assessment.



(a) (b)

Figure 2. (a) Mean Sexual Functioning Questionnaire (SFQ) Total scores as a function of time. (b) Mean SFQ Sexual Functioning Questionnaire (SFQ) Total scores as a function of gender and time.



(a) (b)

Figure 3. (a) Mean Sexual Functioning Questionnaire (SFQ) – interest subscale score as a function of time. (b) Mean Sexual Functioning Questionnaire (SFQ) – interest subscale score as a function of gender and time.

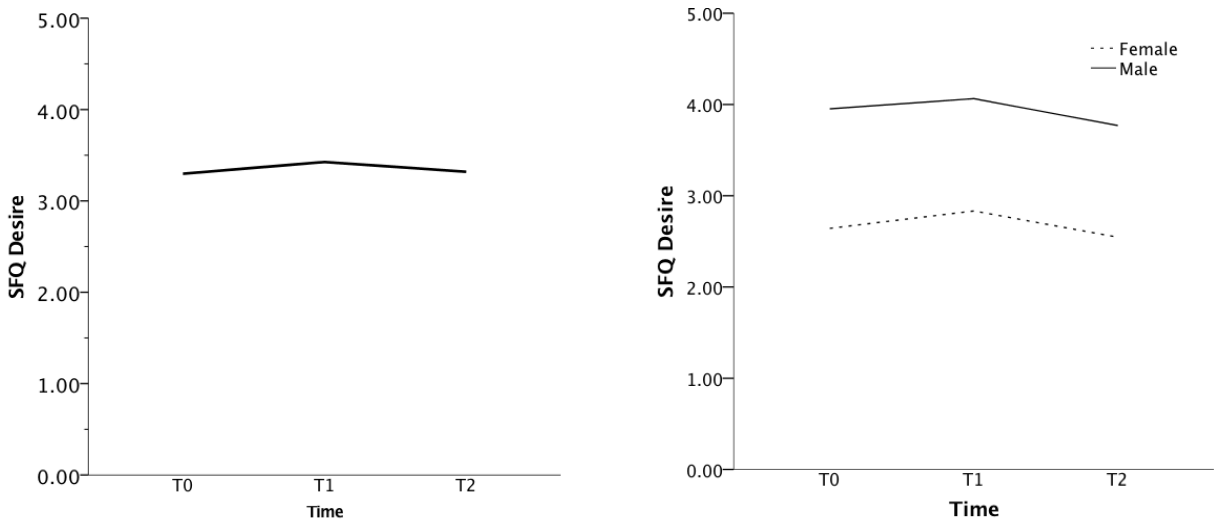


Figure 4. (a) Mean Sexual Functioning Questionnaire (SFQ) – desire subscale score as a function of time. (b) Mean Sexual Functioning Questionnaire (SFQ) – desire subscale score as a function of gender and time.

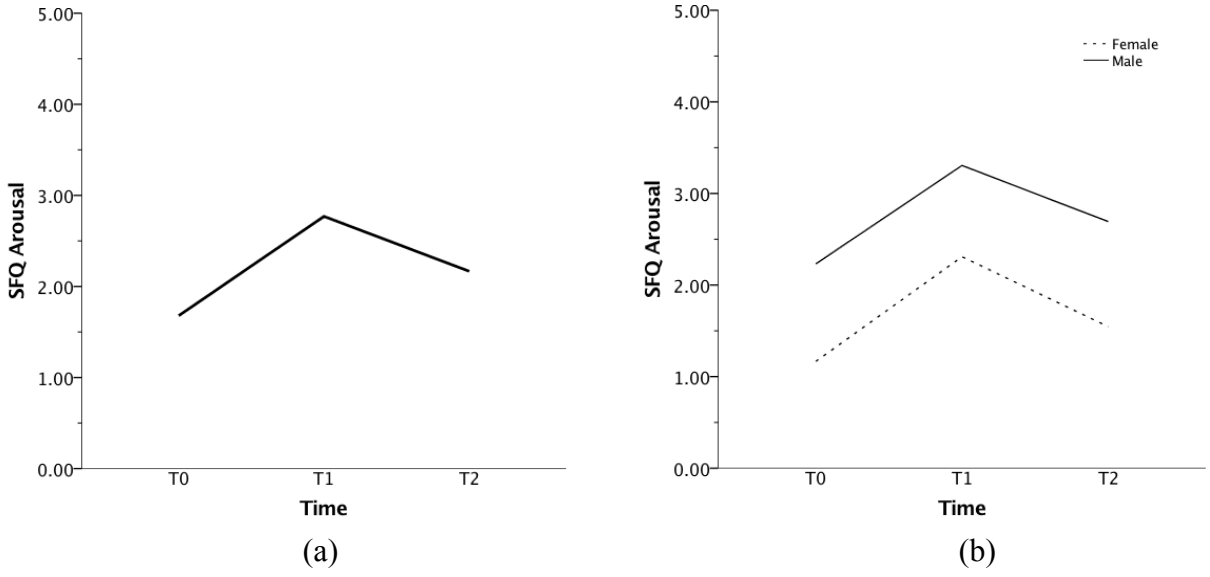
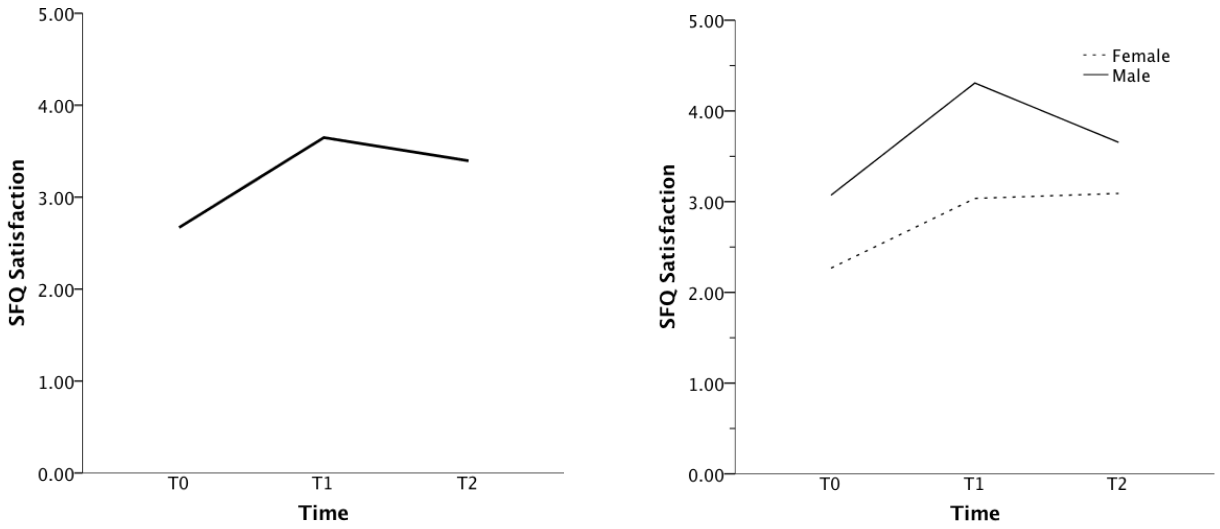
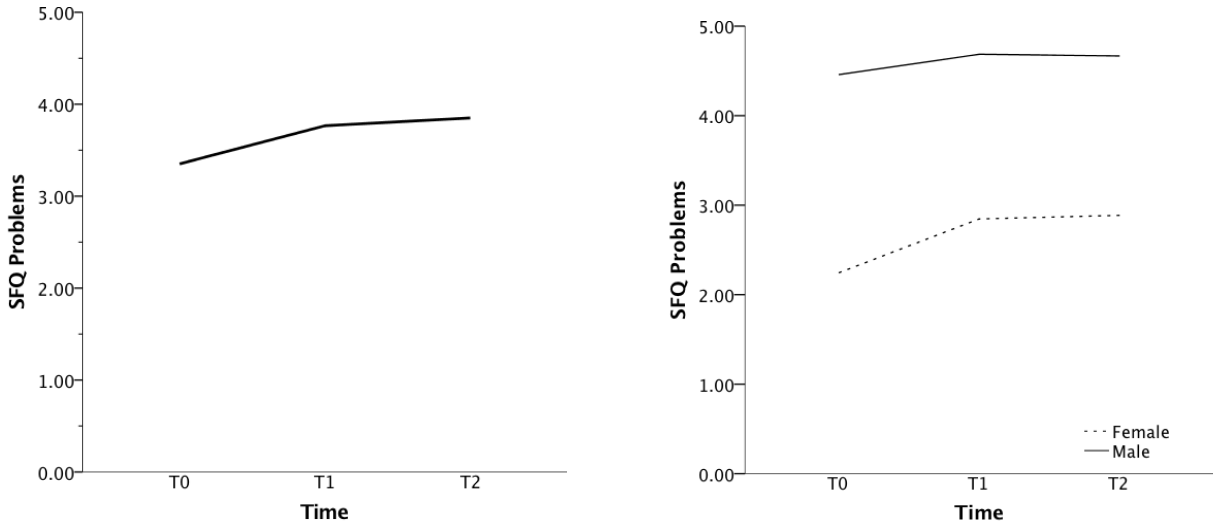


Figure 5. (a) Mean Sexual Functioning Questionnaire (SFQ) – arousal subscale score as a function of time. (b) Mean Sexual Functioning Questionnaire (SFQ) – arousal subscale score as a function of sex and time.



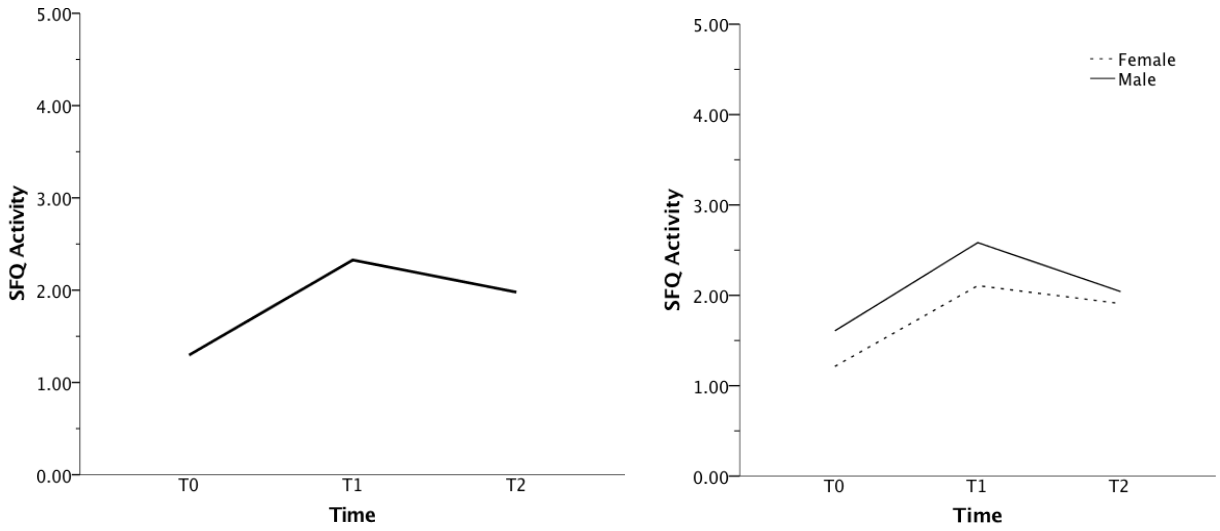
(a) (b)

Figure 6. (a) Mean Sexual Functioning Questionnaire (SFQ) – satisfaction subscale score as a function of time. (b) Mean Sexual Functioning Questionnaire (SFQ) – satisfaction subscale score as a function of gender and time.



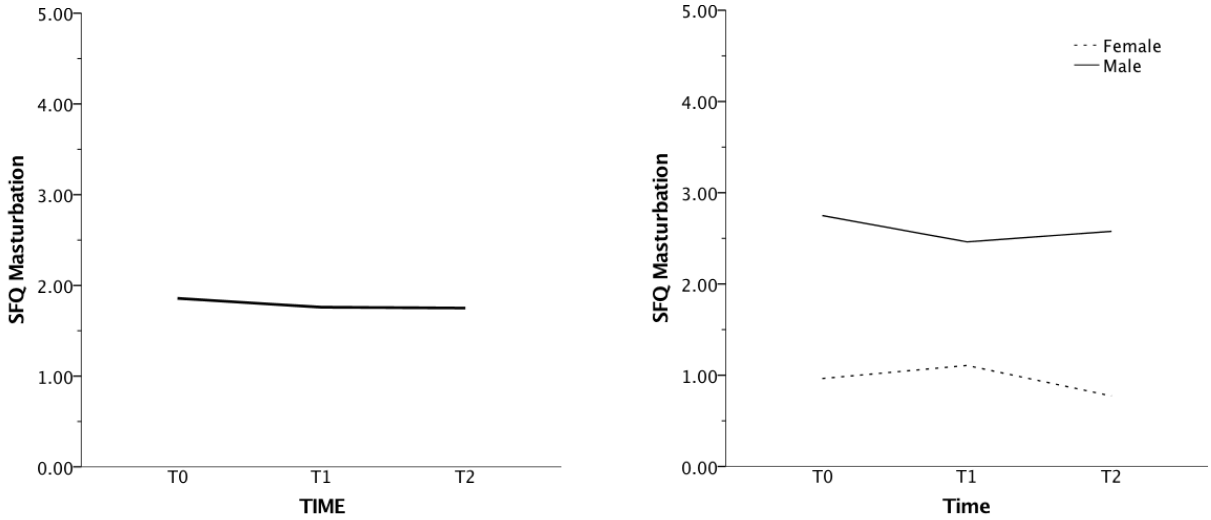
(a) (b)

Figure 7. (a) Mean Sexual Functioning Questionnaire (SFQ) – problems subscale score as a function of time. (b) Mean Sexual Functioning Questionnaire (SFQ) – problems subscale score as a function of gender and time.



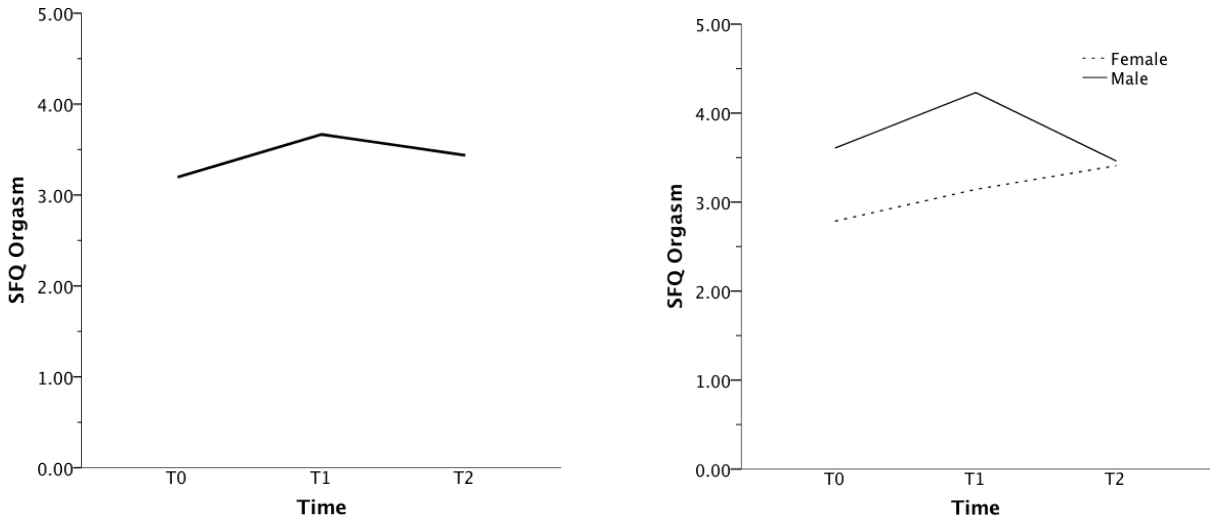
(a) (b)

Figure 8. (a) Mean Sexual Functioning Questionnaire (SFQ) – activity subscale score as a function of time. (b) Mean Sexual Functioning Questionnaire (SFQ) – activity subscale score as a function of gender and time.



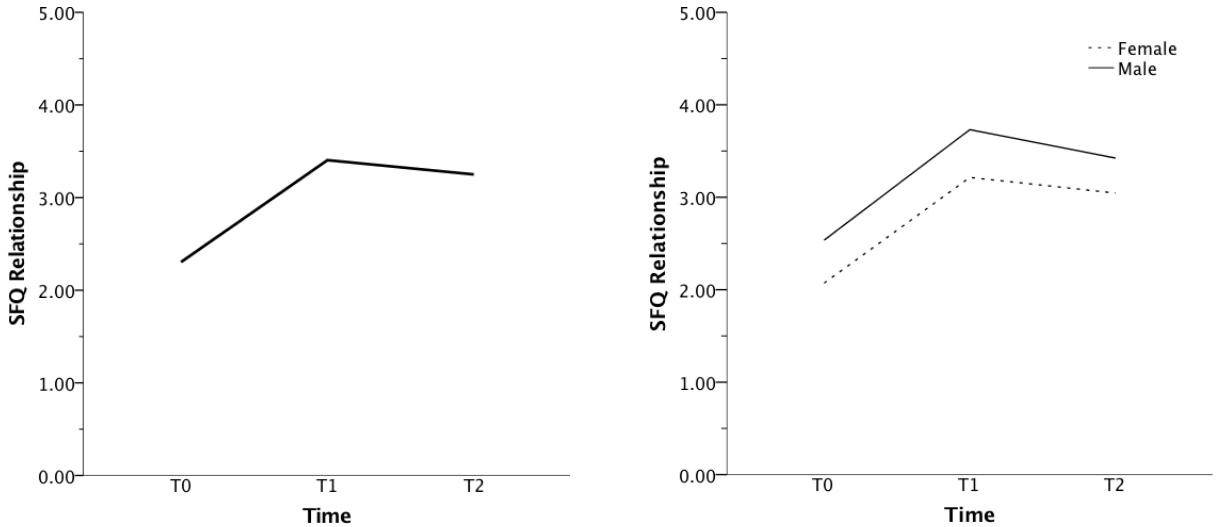
(a) (b)

Figure 9. (a) Mean Sexual Functioning Questionnaire (SFQ) – masturbation subscale score as a function of time. (b) Mean Sexual Functioning Questionnaire (SFQ) – masturbation subscale score as a function of gender and time.



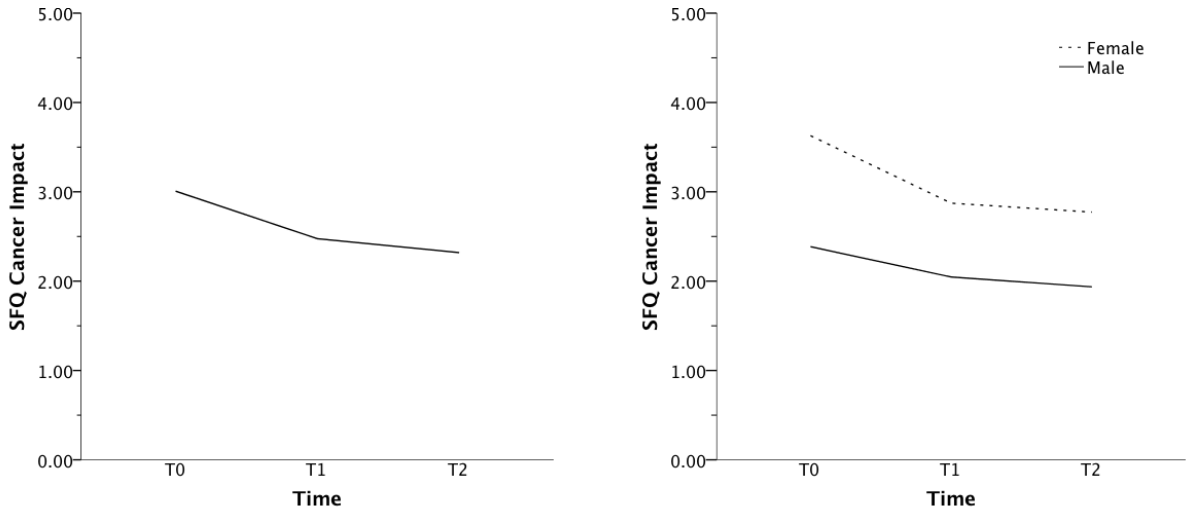
(a) (b)

Figure 10. (a) Mean Sexual Functioning Questionnaire (SFQ) – orgasm subscale score as a function of time. (b) Mean Sexual Functioning Questionnaire (SFQ) – orgasm subscale score as a function of gender and time.



(a) (b)

Figure 11. (a) Mean Sexual Functioning Questionnaire (SFQ) – relationship subscale score as a function of time. (b) Mean Sexual Functioning Questionnaire (SFQ) – relationship subscale score as a function of gender and time.



(a) (b)

Figure 12. (a) Mean Sexual Functioning Questionnaire (SFQ) – cancer impact subscale score as a function of time. (b) Mean Sexual Functioning Questionnaire (SFQ) – cancer impact subscale score as a function of gender and time.

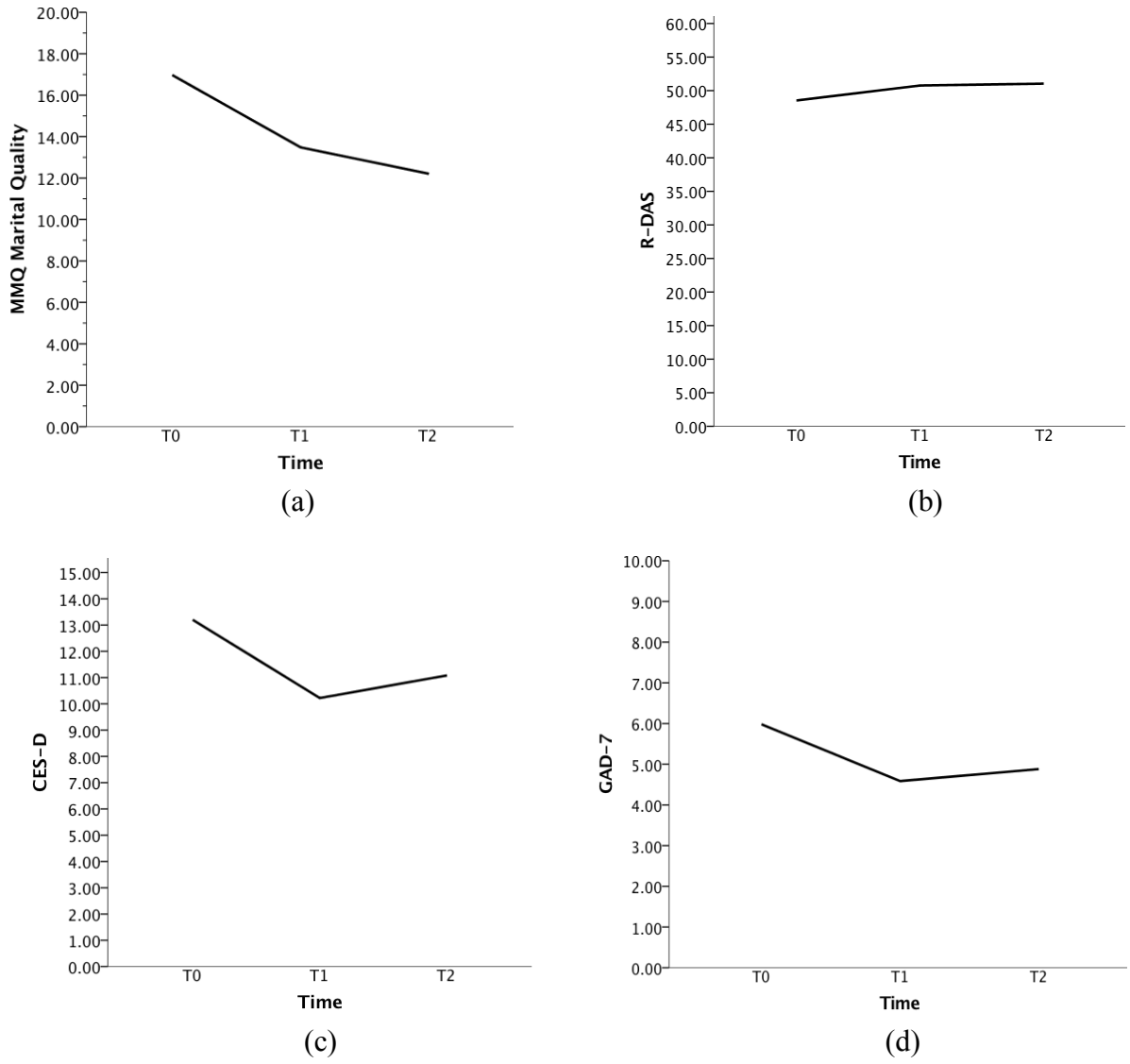


Figure 13. (a) Mean Maudsley Marital Questionnaire (MMQ) – marital quality subscale score as a function of time. (b) Mean Revised Dyadic Adjustment Scale (R-DAS) score as a function of time. (c) Mean Centre for Epidemiological Studies Depression Scale (CES-D) score as a function of time. (d) Mean Generalized Anxiety Disorder Assessment (GAD-7) score as a function of time.

Treatment expectancy and outcome.

Treatment expectancy was assessed after the pre-screening interview and prior to commencing the intervention as part of the baseline questionnaire (T0). The mean treatment expectancy was 4.63/10 (*SD* = 2.56, range 1-10). Multiple linear regression analyses revealed that after controlling for length of relationship and symptom severity (BCPT symptom checklist scores), treatment expectancy did not significantly predict treatment outcome, such that no association was found between participants' treatment expectancy scores and their post-treatment (T1) scores for all outcome variables, including program satisfaction scores. This association was non-significant when the analyses included all participants (*N* = 28) as well as when separate analyses for males (*n* = 14) and females (*n* = 14) were conducted.

Subjective Experiences

Of the fourteen couples (*N* = 28) who participated in the study, two couples did not complete the post-treatment satisfaction survey and three couples did not complete a post-treatment interview, with a total of ten couples completing both. Therefore, all but one couple (C001); (who did not complete either the satisfaction survey *or* interview), are represented in the qualitative analysis. The mean elapsed time between the final session and the post-treatment interview was 5.09 months (*SD* = 2.64, range 1-10). With the exception of one couple, who completed the post-treatment interview one month after completing the intervention, all couples completed their post treatment interviews after the 3-month follow-up timepoint.

Text pertaining to couples' experiences with the psychosexual counselling program, including the areas of interest described in the methods section, was examined and organized into categories. The first stage of the analysis yielded 81 lower order themes, which were then arranged into 16 sub-themes. These sub-themes provided the defining features for the six main

themes. A hierarchical representation of the main themes and their defining features are described in Table 6.

Theme 1: General Program Feedback. Participants' overall thoughts about the program and their experiences were classified according to positive or negative aspects, as well as recommendations for improvement.

1.1 Positive aspects. All participants (n = 26) acknowledged liking the program and/or finding it helpful overall in one or more ways. Five participants commented that the program had a *good progression and pace of sessions*, and appreciated "the progression through a series of steps leading towards tougher issues" (C018M). While the ultimate goal of the intervention was to improve couples' sexual relationships, couples liked that this was achieved in a gradual way that "was like a slow deepening on…how [couples] interacted towards each other" (C007F).

Four participants described the program as having a *good foundation with depth and breadth of topics*, that provided couples with a breadth of knowledge and resources relevant to breast cancer and sex. In the words of one participant, "It put together all the partial information that I've received before from different sources, taking into account the physical and mental issues. I liked…the holistic approach of the program" (C013F). Similarly, three participants described the session content as *informative and purposeful.* In the words of one partner, "Each session had a purpose, and the exercises…helped my wife and I prepare for the next session" (C006M). Participants (n =3) also appreciated that the program content and goals were *specific to breast cancer*.

Half of the participants (n = 13) expressed appreciation for the *tools, strategies, and resources* they received throughout the program, and spoke about "the amazing impact just a

few simple tools had on our lives" (C011F). Another participant, who requested information about a specific problem, expressed her appreciation for additional resources in this regard:

> *"The specific problem that I had [with] vaginal dryness [and] pain…we talked about it and we got the solution… I am much better now….[the facilitator] gave me…information that there are organic lubricants…before I tried one that I found over the internet but it didn't work…I tried so many, I was giving up…I was in pain [and thought] maybe this is not for me anymore, and I didn't know what to do. It was encouraging to find something that works." (C013F)*

Many (n = 7) felt that the program had been *tailored and personalized* to their specific difficulties and needs. In the words of one partner, "The program was adjusted for who we were as a couple…to deal with what our issues were, and not try to get us to a pre-determined point" (C005M). Another participant echoed this sentiment:

> *"I feel like she really tailored it to us…it almost didn't feel like we were going through a research project…I just felt it was totally geared to us…like it was almost imperceptible that there was something she was trying to cover that week" (C004M)*

When reflecting on their experiences of participating in the intervention, the majority of participants (n = 21) cited the opportunity to have a *safe platform for discussion* as an especially helpful aspect of the program. Nearly half of participants (n = 12) enjoyed having a *forum to express thoughts and feelings*. As one woman described the impact of having been able to talk openly about her previous experiences in session:

> *"I hadn't cried a lot through everything that I went through and…when I cried with her for a couple of sessions, it was probably the first time that I really let it go and that I cried in front of [my husband]. I didn't really cry in front of you (referencing husband)" (C015F).*

In response, her husband shared, "Nope (referencing wife). In those sessions, even…I did cry myself" (C015M). Others commented similarly on how the intervention afforded them the opportunity to share their experiences with each other, and to broach topics that otherwise would not have been discussed:

> *"I think really it was the forum to be able to listen to [my wife] and her feelings, to be here and explain feelings, and for me to discuss things impacting me…And it was somewhat regular as it went along…to have a dedicated forum to get these things out in the open. I think it was helpful." (C012M)*
>
> *"It's been helpful because you basically open the doors to letting your emotions, or letting your partner's emotions or feelings come out. Otherwise…if we didn't go through with [the program], basically I wouldn't have known, or [my wife] would have felt more pressure because she wouldn't have known how to tell me or we wouldn't have discussed it." (C009M)*

Correspondingly, having a safe platform for discussion provided couples (n = 7) with an *opportunity to better understand their partner*, which created some clarity regarding the challenges each partner was facing and how to move forward. As one partner reflected, "It got me to think more…about [my wife's] feelings towards her breast cancer and reconstruction, what she was expecting [from] me for our sexual relationship" (C015M). A second partner shared, "It kind of hit home because now it was like 'okay, I didn't know this'…it was just [a] light being shed on everything, the fog being lifted, and [I understood] exactly what we were dealing with" (C009M).

More generally, the program provided couples (n = 6) with a *dedicated time to talk* that they may not have made for themselves otherwise, which instilled couples with a sense of accountability. For example, one partner shared:

"We made time and we're sitting here and we're talking. Otherwise, life gets in the way and even though you would like to talk, sometimes you can't talk because the kids are around, or I'm leaving, coming, she's leaving, coming. So, by having a [dedicated time and space] it basically made you have to talk." (C009M)

The program also provided couples (n = 8) with a *space to discuss sensitive topics (including sex)*. In the words of one participant, "It was really good to have the opportunity to talk about sex with [my husband], because we never talk about it" (C013F). One woman spoke about how this safe space allowed her to revisit issues that felt unaddressed or unresolved:

"[Having] an opportunity to revisit issues for me that are not, kind of, dead in the water…[and] are still important to me…[but that] I don't really have an opportunity to articulate because…no one's asking me about it…So, [it allowed me to] revisit some of those feelings of…loss and sadness which aren't gone, just kind of…buried or compartmentalized." (C012F)

Given that many couples had not previously talked about their sexual relationship and associated challenges, or that previous conversations had not led to successful resolutions, they (n = 11) found it particularly helpful to have these *professionally guided conversations.* As one partner put it "By having a third party…it was easier for me to share my feelings, because I wasn't really talking to [my wife…it was kind of easier, [to talk to] a mediator" (C009M). Another participant expressed similar sentiments:

"My partner and I have been struggling with our sexual relationship for several years now. We have tried to discuss and improve it on our own but haven't been very successful. It was helpful having an unbiased third person involved to encourage further discussion and to ask meaningful, or more challenging, questions that we would have not done so ourselves." (C006F)

Some participants (*n* = 3) expressed that having a platform for discussion *validated experiences and difficulties*, which as one partner shared "made [us] feel confident that we were normal and that the challenges we are facing are not any different than any other couple's challenges" (C006M).

Given their sensitive and often emotionally laded nature, participants (*n* = 6) expressed that some of the conversations and topics explored during the sessions were *challenging (but helpful)*, with one participant describing them as "challenging and scary, but very enriching" (C015F). The utility of these challenging conversations was echoed by another participant:

> *"What's challenging was where [the facilitator]…pushed us to discuss issues that we weren't comfortable with…All of that was tough, but I also understand that the tough moments and the parts that I didn't like were probably the parts that were most important. So, it's a double-edged sword. The parts I don't like are the parts that probably helped me the most." (C018M)*

1.2 Negative Aspects. When asked about the aspects of the program they found challenging or that were less enjoyable, some participants (*n* = 4) reported struggling with the *pace of the program* and found that it moved too quickly. For example, one participant stated, "The hardest part was the sheer volume of material that was covered" (C005F). One participant stated that he and his wife encountered challenges with respect to *finding time to schedule sessions* over the summer months when "it got to the point where it seemed to drag on" (C008M).

1.3 Room for improvement. When prompted, most participants (including those who gave positive feedback) offered one or more suggestions to improve the program (*n* = 22). With the exception of one participant who would have preferred shorter sessions, more than half of participants (*n* = 16) indicated that they would have benefited from *longer or more*

sessions. As one participant commented, "Personally, it all went a little too quickly. I would have done better in an eight-week or ten-week program" (C014M). Similarly, some (n = 6) felt that having a *follow-up or booster session* would have been helpful with respect to maintaining the momentum they had gained during the program.

Four participants expressed an interest in receiving *extra modules or resources* related to specific content including "education [about the physical changes] and anatomy [for my partner]" (C009F) or a "a module designed for the caregiver" (C007M). Three participants would have liked the opportunity to receive *individual sessions or check-ins*, which as one participant felt "may help to ease[into] the next sessions" (C013F). Similarly, another participant suggested that "If someone's having trouble…or has questions…[an individual check-in would make it] easier to figure out why and what to do" (C009F).

Two male participants indicated that a *greater explanation of sessions, exercises, and goals* would have been helpful, with one partner expressing, "I think I would have maybe enjoyed a little more of an overview of how the modules were organized...[and what they] were trying to achieve…I think that she might have given us that, but I don't really remember" (C018M). It is worth noting that his female counterpart did not share this experience, clarifying that, "I don't have the same critique as [my husband]…I was happy with the explanation and overview myself" (C018F).

Theme 2: Experiences with Exercises and Homework. Participants' overall thoughts about completing exercises and homework, along with feedback regarding specific exercises, were categorized according to positive and negative aspects.

2.1 Homework General

2.1a Positive Aspects. Over half of participants (n = 14) identified at least one aspect of the homework they liked and/or found helpful. Seven participants acknowledged *liking all*

of the assigned homework/exercises, because, as one participant put it, "[the homework was a] big piece of the program that make it beneficial" (C012F). Accordingly, one participant expressed her satisfaction with all of the major homework components, expressing "Sensate focus, intentional dialogue, intimacy wish list were the big three. We liked them all" (C018F).

Being assigned homework also *helped couples stay committed and accountable* (*n* = 10), because as one participant remarked "homework…kept us on track" (C004F). The act of scheduling homework also encouraged couples to carve out a dedicated time to focus on their relationship:

> *"I think the homework was actually scheduling time for yourselves even though it wasn't onerous in what you had to do in the time. It was just scheduling time whereas, you know, when you didn't get out your day timers or whatever it is, you can't find waking time to do it." (C012M)*

Similarly, the homework provided couples with the *opportunity to prioritize time together and reconnect* (*n* = 4). As one participant explained, the homework gave him and his partner permission "to take a break from doing our chores or doing the responsibilities that we had in front of us, and just set that time to kind of get back to the basics and enjoying spending time with each other" (C017M). Accordingly, being assigned weekly homework sometimes *led to spontaneous scheduling* of additional activities or time together (*n* = 2), with one participant highlighting how "the whole concept made us think of things that we could do together" (C015F). One participant expressed that in addition to the assigned homework, *exercise check-ins and discussions* allowed this couple to gauge their "progress from the week before" (C017M).

2.1b Negative Aspects. Participants identified various challenges associated with completing the homework and/or elements they disliked, the majority of which centred around

scheduling the homework. Most notably, several participants (*n* = 10) spoke about the ways in which their *busy lives interfered with homework*, which created a barrier to finding the time and privacy to complete some of the exercises. In the words of one participant, "Doing the homework itself wasn't difficult at all, it was just finding [the time]." (C009M). Another partner shared similar thoughts regarding the challenges of finding dedicated time alone:

> *"Because of various commitments, we hadn't been able to perform any of our homework one week. And it wasn't because of a lack of knowledge about it, and knowing that we had to do it…we wouldn't have time alone until literally twelve o'clock at night and then we were just…too tired or…couldn't find the right time." (C012M)*

Some (*n* = 6) reported that the volume of homework assigned homework occasionally created extra *pressure of completing homework in one week* (even for those who we able to complete assigned homework). As one participant explained, "The thing that felt awkward was the timing, [because] sometimes we have three exercises in one week and it was like feeling pressured" (C013F). Correspondingly, some couples (*n* = 5) *needed more space between sessions* in order to complete the assigned homework in a way that felt meaningful and not rushed.

In some ways, participants (*n* = 3) found the homework the be *awkward or forced*, mostly on account of engaging with each other in a way that they were not accustomed to. In the words of one participant, "It's just not how you would normally be…It's not how you would normally interact…It's not spontaneous…It's not what you're used to" (C009F). Some (*n* = 4) participants described the homework as a c*hallenging but necessary/helpful* component of the program. As described below, scheduling time was often the biggest challenge, but was also recognized as important for the relationship:

"Some of the timeframes to complete exercises were challenging to get done. But I guess that was the whole point too. It makes your intimate relationship a priority….when you have a family and life happens and sometimes it's just hard to complete those schedules. But…I also see that it's really important to make the homework a priority and to not keep putting things in front of it." (C018F)

"We weren't used to[making] time for us, but we are used to it now so it doesn't seem like a big deal. But at the time…to schedule two hours in the next week… it seemed like a lot because we only get about an hour each night together; but I don't think it was too much, I think it was absolutely necessary." (C011F)

2.2 Sensate Focusing

2.2a *Positive Aspects.* Approximately half of participants (n = 12) expressed that the sensate focusing exercises were enjoyable and/or helpful in some way. Four participants provided *general feedback* regarding their enjoyment of the sensate focusing, with one partner describing it as "fantastic" (C014M), and another expressing "I loved it" (C009M). Approximately one third of participants (n = 8) referenced the theme of *relearning how to touch each other as a way back to sex* as a helpful feature of sensate focusing, because as one participant put it, "the sensate focusing was a perfect way to start touching each other again" (C014M). Another participant shared, "[It] helped me to get more comfortable with the intercourse" (C013F). Others remarked similarly on how the sensate focusing exercises reintroduced physical intimacy into their relationship:

"I think [the sensate focusing] helped a lot. It was…baby steps, from not wanting to be touched in my right breast to… just cuddling and getting used to [my husband] touching me there…Then, you know, taking it to the next level." (C017F)

In addition to reconnecting with their partners, two participants felt that the sensate focusing gave them the *opportunity to explore their body and new sensations.* One woman, who had referenced her altered body as the primary barrier to resuming her sexual relationship explained:

> *" It actually allowed me to explore…I had a single mastectomy…that area, and in back of my arm…at the time, was very…numb or painful… physically I felt like I wasn't getting any better…So, the sensate focusing actually allowed me to witness sensation in that area, that I would always either feel numbness or pain...So it allowed me to explore it in a way that it didn't just have to be numbness or pain… and it just changed the way I thought [about my pain]…like my brain was definitely on board because I started to discover parts of my rib cage that would have some strange sensations…my body was my own little experiment." (C017F)*

2.2b Negative Aspects. Several participants (*n* = 7) experienced the sensate focusing exercises as *uncomfortable or awkward* (*n* = 3) and/or *did not feel that it applied to their situation* (*n* = 5), largely because it was experienced as counterintuitive to couples' usual sexual routines or scripts.

2.3 Intentional Dialogue

2.3a Positive aspects. The majority of participants (*n* = 18) enjoyed the intentional dialogue exercise and/or found it to be helpful. Ten participants identified the intentional dialogue as their *favourite exercise*. Many participants spoke about how the intentional dialogue exercise *fostered understanding and empathy* between partners (*n* = 11), because as one participant remarked, "you can't really read each other's minds…[so] the mirroring exercises, listening, and repeating what you heard…[made sure] that sure you heard the other person" (C014F). In the words of another participant, "It forced you to listen

and…empathise…[to] basically shut up and listen to the other person" (C018M). Other couples commented similarly that shifting their style of communication deepened their understanding of one another:

> *"It really helped us communicate in a way that we hadn't before…it just forces you to consider the other person's perspective and to empathize and do things you wouldn't normally do when you're trying to defend your position." (C004F)*

Participants (*n* = 3) also used the intentional dialogue as an opportunity to *address topics they hadn't looked at* both within and outside the context of therapy. As participants (*n* = 5) reflected on their experiences of practicing a new communication style, they expressed that the intentional dialogue provided them with a *powerful foundation for moving forward,* that subsequently improved their communication. As one partner remarked, "It really helped us communicate in a way that we hadn't before… it also helped beyond the study. I think it's something that we've used since then…having that conversation through the lens of the intentional dialogue has helped us" (C004F). One participant described how the intentional dialogue enhanced communication in a way that extended beyond their sexual relationship.

> *"We always said that we were going to be effective communicators with each other and always talk about everything and anything. And it was a good exercise to help us see how our communication could kind of grow…we're not always going to be having sex every single second of every single day of every single moment, but we're always going to be talking, communicating with each other." (C007M)*

2.3b Negative Aspects. Some participants described the intentional dialogue exercise as *uncomfortable and/or awkward* (*n* = 2) or felt that it *did not apply to their situation* (*n* = 1). One participant found the intentional dialogue, "difficult because we hurt a lot when talk about

feelings" (C013F). Another was "least fond of the [exercise]…[because it was] too staged for my wife and I who for the most part have good partnership communication ability" (C008M).

2.4 Intimacy Wishlist

2.4a. Positive Aspects. Only two participants explicitly acknowledged the intimacy wish list exercise as being *helpful and enjoyable*, with one participant describing it as "revelatory" *(C018F).*

2.4b. Negative Aspects. One participant described the intimacy wish list as *difficult and confusing*.

Theme 3: Experiences with eTherapy. Despite some of the challenges associated with the provision of eTherapy, participants' feedback regarding this modality was positive overall.

3.1 General modality feedback. When compared to traditional, in-person, therapy, the majority of participants (n = 21) reported being satisfied with the online delivery of the intervention. Four participants commented on their overall *positive experience* with the online delivery and eTherapy platform. As one participant stated, "I find that the video contraption really worked out well" (C004M). Another participant described her initial hesitance but ultimate satisfaction this way:

> *"You know, to do these sessions on the computer via [VSee]…we've never done therapy or anything. So, you have certainly a natural reservation about it. You don't know what exactly you're going into, but it was very successful for us." (C015F)*

Six participants acknowledged that receiving therapy using video-conferencing software was *comparable to in person and felt personal,* in large part due to the incorporation of the visual along with the auditory aspects. One partner described, "It feels like we're in person…. I'm actually looking and sensing your expressions and you can see mine and we're talking. So, for

me nothing was lost" (C009M). Similarly, for other participants, that personal connection was experienced despite the physical distance and electronic interface:

> *"[My partner] doesn't have any experience with a counsellor face to face. I have been in therapy a couple of times, and I can say with certainty there is no difference, in this particular case. I don't know if a different counsellor in a topic maybe it would have been missing something but in this case, it worked just perfectly." (C011F)*
>
> *"I felt like the software that we used to communicate…almost felt like we were sitting with her…we had her propped up on the island on the iPad and, even though it was all done remotely through the internet, it still felt personal." (C004F)*

Other participants (n = 3) expressed that although *in person would have been ideal* they were nonetheless *satisfied with the online delivery.* Participants (n = 7) highlighted that the use of eTherapy was *more personal than phone-based therapy*, and that it was helpful to see the facilitator because, as one man put it, "It creates accountability. Just talking into a telephone doesn't" (C0014M). Echoing this point, another partner commented, "If it would have been a simple [telephone conversation]…we might not have bought into it quite as much" (C008M). For another participant, being able to see the therapist, made her "feel comfortable [because]…it makes you feel like they're being attentive" *(C007F).* Thus the notion of greater accountability through visual contact worked in both directions.

3.2a Positive Aspects. Participants (n = 23) referenced various elements that contributed to their satisfaction with and/or preference for therapy delivered via video-conferencing. Many (n = 13) spoke about the multiple ways in which the online platform created a *safe and comfortable setting.* For example, seven participants expressed that therapy from home created a *comfortable and relaxing environment,* which was conducive to fostering an open dialogue. As one woman explained, "We were at home, [we were] more

comfortable…I was in my PJs most of the time. So, it was definitely a relaxed environment and it facilitated us having more of a free-flowing conversation" (C015F). One partner described "hugging each other the whole session," (C004M) more than he likely would have in office-based sessions. Another participant remarked on the flexibility and familiarity of being in a home environment, and how this enhanced his comfort:

> *"I think even though it was face-to-face…we still felt more comfortable being in our own home. Sometimes we had the session on our couch, sometimes we had the session while we were sitting up in bed, sometimes we had it at the dining table. So, the flexibility of being anywhere and being comfortable you know at home, again, was - is another benefit for us to do it that way." (C007M)*

Participants (n = 7) also shared that when compared to in person therapy, the *online distance* created by eTherapy actually helped to *enhance comfort levels* because "you're present there with the therapist, but you're not totally exposed" (C018F). Other participants remarked similarly:

> *"I don't know if actually having that little bit of distance actually made it feel almost safer…It's just slightly less intrusive to have somebody on a video conference call as opposed to in your office, especially talking about something so intimate" (C012F)*
>
> *"I think that the medium…worked surprisingly well and may even have worked better than if we were to get together in person, because it provided a certain amount of intimacy but also provided a certain amount of distance and separation." (C018M)*

Participants also appreciated the opportunity to receive therapy from the *convenience of home* (n = 5) as one woman put it, "Therapy at home! What could be better" (C015F). Another participant liked that "you can get up and go to the washroom, get something to drink. I thought that worked" (C018M).

Nearly three-quarters of participants (*n* = 18) referenced *flexible and convenient scheduling* as an advantage of eTherapy and the availability of late-night sessions in particular without which one partner was "not sure when we could have made time for that" (*C011M).* Participants (*n* = 12) also spoke of the multiple advantages associated with *eliminating the challenges of traveling* to an office or hospital including not having to worry about childcare, saving time, and eliminating the frustration of dealing with traffic which could negatively impact "your attitude when you arrive to a session" (C013M). Another participant spoke about the more seamless transition from the session to their everyday interaction and dialogue:

> *"I think that when you're done…it's easier to continue the conversation…as opposed to when you leave and then you go home and the whole…because it was fresh. It was there...you had emotions and feelings still, you know. They were still warm and hot, not cooled down with the drive home." (C009M)*

Several participants (*n* = 7), including couples living in the Greater Toronto Area, stated that the online modality *made support accessible*, and that participation may not have been possible had the intervention been delivered in person. As one female participant stated, "We do not live in the same city as [the facilitator], so we would not have been able to take part in the study if we had to meet up with her in person" (C006F). Other couples commented similarly about how the online modality eliminated barriers to obtaining support:

> *"If it wasn't online, I don't think we would have been able to do it. Like hands down. Yup, like it wouldn't have been something, that I would think we could manage, and commit too. So, the fact that it was online, was, was a deal breaker." (C017F*)
>
> *"While we were doing the program, I was working until 8:30pm. So, for us to try to drive somewhere, or find somebody and have like an hour-long session and then drive back, we would have been so exhausted. And [my wife] was working, starting at like*

six o'clock in the mornings. It's just, it wouldn't have worked for us. Plus, we would have been limited to some counsellor that would have been local, versus [this facilitator], I don't think she was local to us. We were able to connect with a better counsellor from a farther distance, because we have the video conferencing." (C007M)

3.2b Negative Aspects. Participants (n = 9) identified two primary challenges associated with the online delivery of the program, but generally indicated that these challenges did not significantly impact their experience. The first was *creating privacy for sessions with children in the home*, and was reported as the most common challenge related to the use of eTherapy (n = 6). For example, one participant remarked that, "I was always sort of nervous that there would be little feet coming down the stairs just as we were talking about something personal that I wouldn't want the kids to hear" (C004F). The other barrier to participation according to a few participants (n = 3) were *challenges with technology,* specifically when poor signal interrupted the sessions:

"It would freeze or - the program that we were using – it was a great program – but sometimes it was pixelated, or [the facilitator] would freeze and we would hear her voice and we wouldn't see her move, kind of thing, or vice versa. So, it depended upon your signal strength, etcetera, etcetera…It wasn't constant enough for us to even notice, but I'm bringing it up because it did happen." (C007M)

Theme 4: Facilitator Feedback. Participants described having a positive relationship with the program facilitator, and highlighted the attributes and qualities that contributed to their positive experiences in completing the psychosexual intervention.

4.1 Therapeutic Alliance. Participants (n = 19) referenced six subthemes describing the therapeutic alliance and their connection to the facilitator. Seven participants described the facilitator as *empathic and genuine*, speaking specifically to ways in which the facilitator was

"tuned in" (C012F) and "connected with my feelings" (C013F). As she described her experience of feeling deeply understood by the facilitator, a third participant remarked "There'd be times, where I'd be like, 'oh my gosh, that's exactly it'" (C017F).

One third of participants (n = 9) described *feeling cared for* by the facilitator. In the words of one participant, "[The facilitator] had compassion. It wasn't clinical, it wasn't matter of fact. It was like, like she cared" (C014M). A second similarly remarked, "We both felt that [the facilitator] was definitely more than just effective. You can see that she cared about our situation" (C007M).

Half of participants (n = 13) spoke about the ways in which the facilitator *created a comfortable environment,* and how the facilitator's demeanor made it easier to discuss difficult and sensitive topics. As one partner expressed, "She made us feel at ease with her, which probably made me more at ease to be able to talk…She got me to talk" (C015M). Another participant commented similarly on how the facilitator's approach created a sense of openness and ease that allowed couples to open up, "I found her very approachable…I think at the beginning it was very uncomfortable talking about certain topics. And the fact that she did it in a way where it was very open… made me feel more comfortable" (C007F).

Participants (n = 7) appreciated the facilitator's flexibility and responsiveness both within and between sessions, and describing her as *patient and accommodating*. As one participant noted, "She was pretty available; if we needed help then she was there, and she was always checking in, and she was very communicative in between" (C011F). Another participant explained how this enriched his experience of completing the intervention, and subsequently "allowed us to kind of want to participate and gain more from this whole [program]" (C017M).

Participants (*n* = 7) appreciated the ways in which the facilitator "*worked with our style,*" speaking to the importance of meeting couples where they were in terms of language, comfort levels, and preferences. In the words of one participant, "She can assess people and work with their style of things, because she could roll with anything" (C014M). Other participants commented similarly on how the facilitator navigated individual experiences and styles:

> *"[The facilitator met us where we were]…terminology wise, comfort wise, and our own versions of describing certain things. She would pick up on those and use those in context rather than using some terms that we might not use. She would work with us in terms of our comfort level, of certain experiences that we did or did not like, and those that we didn't think would be beneficial to us, or had tried." (C012M)*
>
> *"I remember her saying she would just echo whatever…terminology we use because given it was about sexuality there were sometimes where you'd have to talk about body parts or acts or whatever and…I just thought that was good for her to put that out there, not just for us, but for anybody that she's dealing with that. She's going to be flexible and adapt to [us]." (C004F)*

Several participants (*n* = 8) endorsed the theme of *liking and feeling connected* to their facilitator, which as one participant expressed "made a huge impact on how I think we felt about it" *(C012F)*.

4.2 Facilitator style and expertise. Participants (*n* = 18) also shared their thoughts about the facilitator's style and expertise, and the ways this contributed to their positive experience. Many participants (*n* = 12) described the facilitator as *competent and knowledgeable,* and benefited from working with a therapist who, as one participant put it, "knows the material, [and] knows how to navigate her way through the world and sexual

relationships" (C0018M). Another partner remarked similarly, "I felt like she was very knowledgeable in a lot of the exercises that she led us through…which got us to either think or got us interested in trying." (C017M). One participant was especially appreciative of the facilitator's knowledge regarding the intersection between breast cancer and sexuality:

> *"What I appreciated most about the program was an opportunity to work with a couples' therapist who truly understands the nuances of how breast cancer impacts relationships. Having the flexibility to work with a therapist…who not only is skilled in couples' counselling but who has an understanding of the multiple ways in which breast cancer impacts physiology, sexual drive, body image, relationships, self-esteem, self-image, and sexuality is unique and special." (C012F)*

Participants (n = 6) found it helpful to have a facilitator who was *skilled at guiding sessions*, and who could "feel the pulse…[of the] the conversation" (C015F). Other participants remarked similarly on how the facilitator stayed on the leading edge of the conversation. For example, one participant expressed, "[The facilitator] has a keen eye and a keen ear. She could really lead the conversation and the discussion in a way that was, like - her sense is where it needed to go" (C017F). Echoing this comment, another participant stated, "She would push a little bit, but not push excessively, and then move on to other things, which I think was a useful technique" (C012M).

Many participants (n = 8) appreciated the facilitator's *insightful feedback and guided discovery.* One couple described the facilitator as "curious without being…intrusive" (C012F), which, as other participants described, facilitated their own curiosity and discovery.

> *"I couldn't even express to [my husband or to the facilitator] why I was feeling a certain way, why I was closed off to certain ideas. But just her talking through and having her trying to get to the root of why I'm feeling a certain way…the questions that*

she asked me…made me think about my answers and made me more open, because…the questions she's asking, I wouldn't have thought of." (C007F)

"There were certain things that were asked, or certain things that were asked [of my wife]…that I would have liked to know and I never asked. So that kind of helped me. So, by [the facilitator] asking it was like 'okay, right on, she'd asked it.'" (C009M)

The facilitator's style and demeanor were generally described as *pleasant and easy going*, which further enhanced participants' comfort levels. (n = 9). As one participant expressed, "She was very laid back; she was very casual but very professional" (C013M). Others commented on the facilitator's use of humour and how this helped to guide some otherwise serious or sensitive conversations.

"[The facilitator was] very personable…her attitude and her humor was very, you know, friendly and light. We had a chance to joke around a lot, which made it more comfortable for us to talk, as opposed to being kind of in like…a very sterile environment." (C007M)

"She was very funny, she was very human…and it really got me speaking out loud for the first time, regarding some emotions that I had gone through and was going through. So, for me…it was a breakthrough in my cancer recovery." (C0015F)

Theme 5: Outcomes and Takeaways. A range of positive outcomes and takeaways were reported by participants across various domains. Only one participant, who struggled to engage in the sessions and with his wife, expressed that the program "did not help with lack of sex" (C009M).

5.1 Outcomes and Changes. Participants (n = 18) spoke about the multiple ways in which the program improved and/or enhanced their relationship. As highlighted in the themes below, couples experienced improvements in their physical/sexual intimacy as well as in their

relational/emotional intimacy. Five participants (each representing a different dyad) spoke explicitly about their *improved sexual relationship and satisfaction*. As one participant expressed, "It allowed my wife and I to explore and rejuvenate our sexual relationship" (C007M). Another exclaimed, "My wife and I were just roommates, but through participating in this program we are back to husband and wife" (C014M). One participant described how she and her husband reconnected as romantic and sexual partners:

> *"Our connection felt stronger …I think we had drifted apart, and my sexuality was… not at the forefront [of our relationship]…It just brought us together in a way that we needed and didn't know how to get there on our own…Showing affection for the other person I found improved…we started having sex again where we hadn't been for probably a few weeks….we had date nights." (C004F)*

Participants (n = 9) highlighted the ways in which the program *increased connection and intimacy.* In one partner's words, "[The intervention] encouraged my [wife] and I to reconnect on a personal level, which also helped us be more [physically] intimate" (C006M). Two women reflected on how their increased connection to their partners enhanced their own personal well-being, with one expressing, "[My husband] and I were…living our own lives...[and so] it was good to get closer, so I feel better now" (C013F). Another commented, "I can't express how much this program has meant to me, how much more secure I feel in my relationship and generally more comfortable with life" (C011F).

The program also *improved communication* for many couples (n = 6), which further contributed to their deepening connection. As one partner described, "My wife and I were able to open new channels of communication and this has led to a greater feeling of intimacy in our relationship" (C011M).

The intervention and associated exercises also helped women (*n* = 3) to feel *more connected and confident with their body*.

> *"I was in a lot of pain and had really limited range of motion, and so it was really hard for me to also get accustomed to [that]…I found that through this program it really allowed me to reacquaint myself with my body and to learn its new signals." (C017F)*

For many participants (*n* = 9), the program has had a *lasting impact* on their sexual and intimate relationship, and has instilled a *hope for the future*. Most notably, couples spoke about taking their experiences learned during the program and recreating these in their lives beyond the program:

> *"[The program] kind of shook into us that what we are doing in those moments are so incredibly important for our marriage, just something to find time to somehow be together, in one way or anything. To do our homework kind of translated into us continuing to do that each week and looking at our calendars and finding time to spend together each week. It's made our marriage so much better for it. It's created this great habit between us that just does wonders for the marriage." (C011M)*

> *"She did leave us with the tools, like she did say, 'you know what, put in a reminder, do a touch point every Sunday, you know, or do a touch point every Wednesday,' which was our time to say, 'you know what, let's check in with each other and see how things are going.'" (C007M)*

Accordingly, these experiences also left couples feeling empowered to maintain these changes in the long-term:

> *"Before [the program], I was thinking that my sexual life would be painful and unsatisfactory the rest of my life. I thought it was part of being older and having had breast cancer. Now I know that there is a lot of room for improvement in my*

relationship and my sexual life, and I'm working on it every day with [my husband]." (C013F)

In contrast, four participants admitted to having *lost momentum gained in the program*. While one participant attributed this loss to her "current medical situation and having to go through long periods of recovery from [subsequent] operations" (C004F), another participant elaborated on the difficulties maintaining the behavioural changes without the guidance of, or sense of accountability to, a facilitator:

"[We were] pretty much left on our own for us to get there, with the necessary tools, which is great. But in the same time… when you're stuck and you don't have someone there and the session ends, you're kind of left with each other thinking, 'okay, we'll kind of push it off, push it off, those exercises.' So, almost kind of guilty, in a sense that we haven't been on top of things that we should…be putting it into practice…I would say we did a couple things weeks after. But as the months came and gone we kind of…went on with our life." (C007F)

5.2 Valuable takeaways. When asked what they found most valuable about the program, the majority of participants (*n* = 22) touched on new or shifting views of themselves, their relationships, and/or their circumstances, which, in turn, translated to subsequent improvements in their relationships.

Participants (*n* = 12) endorsed *new awareness* and a range of *insights,* which they found validating and informative, "that were 'ah ha' moments" (C005F) in the words of one participant and "enlightening" (C014F) for another. One partner shared, "I'm glad that I ended up doing it… it shed some light on a lot of things for myself and not only about her, but about myself" (C009M). A valuable insight shared by several participants was "that there is an important psychological factor in the sex issues after breast cancer" (C013F).

Many participants (*n* = 9) spoke about the ways in which *accepting a new normal* reduced their distress and changed their approach to sex. As one woman put it, "I don't need to be fixed. We have a new normal, and a purple sky can be just as lovely as a blue sky" (C005F). A partner remarked similarly "[Our sex life] may not be the same as before, but it's not dead" (C007M). Other participants elaborated on how this acceptance positioned them to better engage in sexual exploration and problem solving:

> *"I think that's the most positive part - that you give the couple the opportunity to understand…and try to accept the changes and how to deal with that; and you might realize that, in terms of the sexual relationship, it hasn't changed that much…There were physical changes and you have to readjust to that and be more patient sometimes, be aware what makes her uncomfortable, why certain things that can be done before can't be done this time, and there's certain new things you can do." (C013M)*
>
> *"Realizing that hey, you know what, it will never be that way again. But, it will be different, and different can also be good, and that there's a lot of different things that we can do that will still make it pleasurable and extremely fun for both of us." (C007F)*

Participants (*n* = 8) also learned the importance of *sharing responsibility for the sexual relationship.* As one partner commented, "[I learned] the importance of sharing responsibility when it comes to our sexual relationship" (C012M). Another partner echoed this sentiment, stating, "We weren't about fixing someone, but fixing us as a couple" (C005M). Accordingly, this new insight reinforced that women were not to blame for their sexual difficulties and that "one partner should not feel responsible for the onus of a couple's sexual relationship" (C012F), with another participant affirming that "I am not 100% of the problem when it comes to [the] sexual aspect of the relationship since diagnosis" (C009F).

Likewise, couples (*n* = 8) acknowledged the *value of communication as a bridge to intimacy and sex.* As one participant put it, *"*We were able to address issues with communication that bled into our sex life, which has made us a much stronger and happier couple" (C011F). Another participant echoed this realization, expressing that, "Communication is key to intimacy and a fulfilling sex life and partnership with my husband" (C015F).

For some (*n* = 4), having been given the opportunity to prioritize time together during the intervention reinforced the *importance of scheduling time for ourselves* that extended beyond the program.

> "*It highlights the exact issue which is that intimacy, like a lot of things, is something that you have to make time for. You just have to make time for it, and I think that was probably the most important lesson from the whole program." (C018M)*

Similarly, some participants (*n* = 4) reflected on their newfound appreciation for the *relationship between sex and intimacy,* and that intercourse was not necessarily the defining feature of a satisfying sexual relationship. In the words of one participant, *"*It's okay to take it slow and not have to rush into full on intercourse…we can be intimate without that" (C014F). Similarly, one partner appreciated that "the program allowed us to focus on our relationship and how we interact, as opposed to mechanical issues of what to do during sex" (C005M).

Theme 6: Final Reflections. Feedback regarding the intervention was overwhelmingly positive, with participants reporting high levels of satisfaction and highlighting the program's value.

6.1 Program Satisfaction. When reflecting on their overall experiences, the majority of participants (*n* = 22) expressed that the program met their expectations and felt that nothing was missing. Over half of participants (*n* = 15) explicitly stated that the program *met or*

exceeded their expectations. While some participants had specific expectations, others were unsure about what to expect and/or did not expect the program to be helpful. As one participant remarked, "When I read the description of the program, I didn't think I would get as much out of it than I actually did. It was a nice surprise" (C017F). Another participant stated, "I expected something different, but I actually came out and got more than I expected" (C007F). One partner described how the intervention met his expectations and provided him with some unanticipated insights:

> *"There was nothing that I wanted to achieve out of it that I didn't achieve out of it. There were some things that came to light because of it that probably would not have in a normal course of a partnership, if you will. So, for me…it did what it was supposed to do and, and I was happy with it." (C008M)*

When queried about aspects they disliked or might be missing, many participants (*n* = 11) expressed that they *wouldn't change a thing* and/or *liked everything.* One male participant, who felt constrained by the manualized format of the sessions and exercises, made several references to his strong dislike of what he described as a "*boot camp" approach to therapy*. This participant struggled to see the value in the prescribed approach, and would have preferred that each session focus on the relational difficulties he had deemed to be most important.

6.2 Program Value. In their acknowledgment of the program's value, participants (*n* = 17) highlighted the importance of this resource, and expressed their gratitude for its availability.

Many participants (*n* = 10) believed that the current intervention *fills a treatment gap* and provides notably absent support for couples affected by breast cancer. As described below, sexuality was typically not addressed by the primary health care team, and support for

sexual difficulties was not made readily available. Accordingly, participants stressed the importance of integrating sexual health support into cancer care:

> *"Nobody ever broached this subject after breast cancer. Nobody. No doc. Not my doctor, not my oncologist, not my surgeon. Like, there's nothing. It's like, 'here you go, surgery, chemo, ah, you're fine, goodbye.' It's a topic that is so needed. And the fact that you're…doing this is amazing. And there should be more of it. Like just, keep going, and reach out further to more couples…After a woman is done with all of the surgery and treatments, this could be part of the follow-up…it should be the next step of recovery…So it's something that really needs to be out there." (C014F)*

> *"As someone impacted by the after effects of breast cancer, knowing that [the hospital] is spending research dollars, time, and resources exploring the psychological and relational impact of breast cancer as it relates to women's sexual health is both validating and reassuring." (C012F)*

One participant also highlighted the program's potential to be adapted and expanded to support other medical populations:

> "*This is designed for breast cancer, but…I think it…could potentially find use in other types of traumatic spaces, whether it be amputations of different sorts or other types of cancers…I think that this has a place to be expanded… If it can be made available to breast cancer survivors, and then it might have value elsewhere as well." (C012M).*

Having been given the opportunity to address their difficulties and needs with respect to post-cancer sexualities that they likely would not have had otherwise, half of participants (*n* = 13) expressed *gratitude for the program* and the associated changes/improvements. As one partner expressed, "I would ditto what [my wife] said for sure. I feel incredibly grateful that this program was available, and is available to people, and would hope that people feel it is

necessary" (C011M). In her final reflections regarding her experiences with sex after breast cancer, and with this psychosexual intervention, one woman conveyed her appreciation for this resource:

> "*Thank you so much for who you are and for what you are doing. This is such a needed program. Sex after cancer is a difficult thing and difficult to discuss with anyone. Doctors, nurses, oncologist- no one talks to you about it! It's a huge part of recovery and you helped me with that! I am so grateful!! Please keep going and…continue this program!" (C014F)*

Table 6

Qualitative Program Evaluation Main Themes and Defining Features

Category	*n*
Theme 1: General Program Feedback	
1.1 Positive Aspects	26
Good progression and pace of sessions	5
Good foundation with depth and breadth of topics	4
Informative and purposeful	3
Specific to breast cancer	3
Tools, strategies, and resources	13
Tailored and personalized	7
Safe platform for discussion	21
Forum to express thoughts and feelings	12
Opportunity to understand my partner	7

Dedicated time to talk	6
Space to discuss sensitive topics (including sex)	8
Professional guided conversations	11
Validated experience and difficulties	3
Challenging (but helpful)	6
1.2 Negative Aspects	11
Pace of the program	4
Finding time to schedule sessions	1
1.3 Recommendations for Improvement	22
Longer or more sessions	16
Follow-up or booster session	6
Extra modules or resources related to specific content	4
Individual sessions or check-ins	3
Greater explanation of sessions, exercises, and goals	2
Theme 2: Experiences with Homework and Exercises	
2.1 Homework General	
2.1a Positive Aspects	14
Liked all homework/exercises	7
Helped couples stay committed and accountable	10
Opportunity to prioritize time together and reconnect	4
Lead to spontaneous scheduling	2
Exercises check-ins and discussions	1
2.1b Negative Aspects	16

Busy lives interfered with homework	10
Pressure of completing homework in one week	6
Needed more space between sessions	5
Awkward or forced	4
Challenging but necessary/helpful	4
2.2 Sensate Focusing	
2.2a Positive Aspects	12
General feedback	4
Relearning how to touch each other as a way back to sex	8
Opportunity to explore body and new sensations	2
2.2b Negative Aspects	7
Uncomfortable or awkward	3
Did not apply to our situation	5
2.3 Intentional Dialogue	
2.3a Positive Aspects	18
Favorite exercise	10
Fostered understanding and empathy	11
Addressed topics we hadn't looked at	3
Powerful foundation for moving forward	5
2.3b Negative Aspects	3
Uncomfortable and/or awkward	2
Didn't apply to our situation	1
2.4 Intimacy wish list	

2.4a Positive Aspects	2
Helpful and enjoyable	2
2.4b Negative Aspects	1
Difficult and confusing	1
Theme 3. Experience with eTherapy	
3.1 General modality feedback	20
Positive experience	4
Comparable to in person and felt personal	6
In person would have been ideal but satisfied with online delivery	3
More personal than phone-based therapy	7
3.2a Positive Aspects	23
Safe and comfortable setting	
Comfortable and relaxing environment	7
Online distance enhanced comfort levels	7
Convenience of home	5
Flexible and convenient scheduling	18
Eliminating challenges of traveling	12
Made support accessible	7
3.2b Negative Aspects	9
Creating privacy for sessions with children in the home	6
Challenges with technology	4
Theme 4. Facilitator Feedback	
4.1 Therapeutic Alliance	19

Value of communication as a bridge to intimacy and sex	8
Importance of scheduling time for ourselves	4
Relationship between sex and intimacy	4
6. Final Reflections	
6.1 Program Satisfaction	22
Met or exceeded expectations	15
Wouldn't change a thing, liked everything	11
"Bootcamp" approach to therapy	1
6.2 Program Value	17
Fills a treatment gap	10
Gratitude for the program	13

Note: *n* refers to the number of participants who endorsed each category.

Chapter 4: Discussion

The purpose of this dissertation was to develop and evaluate an online psychosexual intervention for couples experiencing sexual difficulties following breast cancer treatment. The feasibility, acceptability, and preliminary effectiveness of the intervention were evaluated using a single-arm, mixed-methods design with concurrent triangulation strategy, with participants completing questionnaires concerning sexual functioning, marital quality, and psychological adjustment at baseline, post-treatment, and 3-month follow-up. Given the small sample size, variations in age and recovery trajectory, along with the well-established unique and individual ways in which breast cancer can alter sexuality, it was anticipated that objective measures may not fully capture the impact of this intervention on sexual relationships.

Accordingly, participants' opinions, attitudes, and subjective experiences were triangulated with the quantitative data as a form of cross-verification and to capture a more nuanced understanding of couples' experiences with this intervention and its delivery, along with its benefits.

The intervention was found to be feasible and acceptable, as demonstrated by high retention, treatment adherence, and satisfaction. There is also evidence to suggest that the intervention was effective at improving sexual functioning and satisfaction; although, as evidenced by decreasing effect sizes, some of these gains were lost at follow-up. The videoconferencing-based delivery of this intervention was also widely accepted by participants, who highlighted several advantages of this modality. Feasibility, acceptability, preliminary effectiveness, and subjective experiences with the intervention, along with their implications for research and practice will now be given further consideration. Emerging considerations for researchers and clinicians involved in the evaluation and provision of psychosexual interventions are also discussed.

Feasibility and Acceptability

The results of this study suggest that implementation of an eTherapy, couples-based psychosexual intervention is feasible for breast cancer survivors and their partners. Fourteen out of fifteen couples (93%) who commenced the intervention completed all six sessions. With the exception of needing more time between sessions in order to complete the homework, none of the participants referenced difficulties accommodating sessions into their schedules. Although not formally monitored, some couples struggled to complete *all* of the assigned homework, based on their in-session self-report during homework debrief discussions; however, the majority of couples completed at least one of the assigned exercises each week (e.g., completing at least one sensate focusing session per week). Couples typically cited the

volume and time commitment associated with the homework, combined with having busy lives and/or familial responsibilities, as primary barriers to completing all of the assigned homework. Accordingly, five couples benefitted from an extra session in the earlier stages of the intervention to address difficulties with homework scheduling. Despite these challenges, participants identified the homework as an integral part of the program that provided an opportunity to practice the strategies discussed in session, created accountability with respect to improving their sexual relationship, and encouraged couples to prioritize time together.

Participants appreciated the format of the intervention, particularly with respect to the holistic approach and gradual progression back to sex; this reaffirmed the design of the intervention, which emphasized emotional intimacy as an important stepping stone to rebuilding sexual intimacy. Many couples expressed that the program felt tailored to their specific difficulties and did not feel constrained by the manualized format or session agendas. Some participants *did* find the pace of the program and volume of the material covered in each session to be challenging, and over half of the participants thought that the program was too short or went by too quickly. Accordingly, participants expressed that they would have benefitted from the addition of at least two sessions as a way of slowing down the pace.

Participants' high satisfaction ratings, along with their generally positive feedback reinforced the acceptability of this intervention for improving sexual relationships. All of the participants found the program to be enjoyable and helpful, with many participants expressing that they liked everything about the program and/or that the program met or exceeded their expectations. Consistent with the literature (Henson, 2002; Karabulut, & Erci, 2009), participants shared that resources for sexual difficulties following breast cancer were not readily available, and that sexual issues were rarely discussed or addressed by their health care

providers. Correspondingly, many couples expressed their enthusiasm and gratitude for this initiative, reaffirming this program's role in filling a notable treatment gap.

Preliminary Effects

The hypothesis that couples would demonstrate improvement in sexual functioning was supported. As evidenced by moderate and large effect sizes, the intervention increased couples' engagement in sexual activities and led to improvements in overall sexual functioning, arousal, and pleasure or satisfaction derived from sexual activities from baseline to post-treatment, with sexual engagement, satisfaction derived from sexual activities, couples' overall satisfaction with their sexual relationship, and the degree to which couples perceived breast cancer as having negatively impacted their sexual relationship being maintained at follow-up. The intervention had a noteworthy impact on couples' overall satisfaction with their sexual relationship, as well as the degree to which they perceived breast cancer as having negatively impacted their sexual relationship, both of which were maintained at follow-up.

It is worth noting that although moderate and large effect sizes were maintained at 3-month follow-up for many of the variables, the decreasing magnitude of effect sizes point towards a trend of treatment gains being lost over time. Given that the absence of sustained improvements in sexual functioning at follow-up is not uncommon in the literature (Brotto, Yule, & Breckon, 2010), the finding that some improvements decreased (e.g., engagement and satisfaction with sexual activities, overall satisfaction with the sexual relationship) and/or were not maintained after three months (e.g., overall sexual functioning, arousal), was not unexpected. A possible explanation for the decrease in gains over time relates to the fact that ratings of sexual functioning were contingent on couples engaging in behavioural changes with respect to their sexual relationship (i.e., having sex). Accordingly, larger effect sizes at T1 versus T2 likely reflect couples' increased engagement in sexual activities over the course of

the intervention, and, as described in couples' subjective experiences, a loss in momentum with respect to maintaining these behavioural changes/gains after treatment has ended.

Separate analyses for patients and partners resulted in similar outcomes, and visual inspection of outcome variables as a function of time (Figures 2 – 13) revealed that change trajectories were also similar. Consistent with previous studies (Scott et al., 2004), women's overall scores tended to be lower than their male counterparts, which was expected given their patient status. There were slight gender differences with respect to sexual activity, satisfaction with sexual activities, and orgasm. While women's improvements in engagement and satisfaction with sexual activities were maintained at follow-up, men showed improvements only at post-treatment. Visual examination of Figure 10 also revealed that women experienced a steady increase in orgasm frequency and quality (with moderate effect size at follow-up), while men experienced an increase at post-treatment, with an eventual decline back to baseline. Two possible mechanisms emerged that may provide some explanation for these differences. First, gender differences may be due to women's patient status, such that women's sexual identity and functioning were more adversely affected by breast cancer, which created more room for improvement than their partners. Indeed, as seen in Figures 6, 8, and 10, there was a convergence of men's and women's mean activity, orgasm, and satisfaction scores at follow-up, with women's activity and orgasm scores closely mirroring those of their male counterparts. Second, the differences could be an indication that couples were engaging more frequently in non-coital sexual activities (i.e., manual and oral stimulation). As Salisbury and Fisher (2014) described, the largest discrepancy between male and female orgasm frequency occurs in the context of penile-vaginal-intercourse, with the majority of men indicating that they usually or always orgasm during intercourse and the majority of women indicating that they do *not* orgasm through intercourse alone (Fisher, 1973; Wade et al., 2005). Clitoral

stimulation is considered to be the primary source of stimulation for eliciting orgasm, which can also occur during intercourse through direct and indirect stimulation (Darling, Davidson, & Cox, 1991; Hite, 1976; Masters & Johnson, 1966). It stands to reason, then, that if couples were more frequently engaged in non-coital sexual activities that subsequently increased women's orgasm frequency, women would also report being more satisfied with sexual activity. Correspondingly, this may also provide some explanation as to why some of the male partners reported that improvements were not maintained at follow-up, such that men may attribute more "traditional" forms of sexual activity (i.e., intercourse) to their sexual satisfaction.

Given the mostly large effect sizes at both time points for all participants, and when men and women were analysed separately, a more in-depth discussion regarding the impact of the intervention on couples' overall satisfaction with their sexual relationship, along with the degree to which participants perceived breast cancer as having negatively altered their sexual relationship, is warranted. Overall satisfaction with the sexual relationship (SFQ-relationship) refers to the degree to which participants were satisfied with their sexual relationship as well as the degree to which they perceived their partner as being satisfied. Sexual satisfaction has been defined and operationalized in multiple ways. For example, Santtila et al. (2007) define sexual satisfaction as "no discrepancy between desired frequency and actual frequency of sexual behaviours," (p. 32). One of the most accepted definitions of sexual satisfaction was proposed by Lawrance and Byers (1995), who defined it as "an affective response arising from one's subjective evaluation of the positive and negative dimensions associated with one's sexual relationship" (p. 268). In a thematic analysis of lay people's definitions of sexual satisfaction, Pascoal and colleagues (2014) found mutual pleasure to be a crucial component of sexual satisfaction, and that sexual satisfaction derives from positive sexual experiences and

not from the absence of sexual dysfunction. Accordingly, in addition to increasing the frequency of sexual activity, and presumably decreasing the discrepancy between desired and actual frequency, participants' increased satisfaction with the sexual relationship, and decrease in the perceived negative impact of breast cancer on the sexual relationship, can be attributed to reduced frustration in terms of positive or satisfying sexual experiences outweighing the negative.

The current intervention did not yield any meaningful improvements in relationship quality and adjustment. However, given that participants' baseline scores were suggestive of positive dyadic adjustment (as indicated by low MMQ scores) and good relationship satisfaction (as indicated by high R-DAS scores) (Arrindell, Boelens, & Lambert, 1983; Crane et al., 2000) these findings were likely due to floor and ceiling effects respectively. The intervention also did not yield any meaningful decreases in mood and anxiety disturbances. However, given that participants' baseline symptoms fell into the no to mild range (Radloff, 1977; Spitzer, Kroenke, Williams, & Lowe, 2006), these findings were also likely due to floor effects.

Subjective Experiences

The objective findings regarding the impact of the intervention on sexual functioning were echoed in participants' feedback regarding their subjective experiences and outcomes. Participants described the various ways in which the intervention improved their sexual relationship and deepened their intimacy and connection. Interestingly, rather than describing improvements (or lack thereof) on specific sexual outcomes (i.e., frequency, desire, arousal, orgasm), participants spoke about the general improvements in their sexual relationship. While one male participant explicitly stated that the intervention "did not help with the lack of sex," the vast majority of participants indicated that their sexual relationship had improved. Some

couples reported having engaged in sex after an extended period of abstinence ranging from a few weeks to six years. Notably, participants expressed how the intervention brought sex back to the forefront of their marriage, and re-established their relationship as sexual partners. Accordingly, participants also reported feeling more connected with a greater sense of emotional intimacy. In many ways, participants attributed these improvements to having relinquished their previous expectations and efforts to reclaim their pre-cancer sexual relationship, and having a greater acceptance of their altered bodies, sexuality, and functioning. Couples' acceptance of these changes not only reduced their subjective distress associated with cancer related sexual changes, it also increased their flexibility and openness to renegotiating their sexual dynamic. Ultimately, by accepting that different does not necessarily mean worse, couples were able to work together in the pursuit of rebuilding a mutually satisfying sex life.

The majority of participants felt that the intervention had a lasting impact, particularly with respect to prioritizing their relationship and continuing to make an active effort to work on their intimate and sexual relationship. With the exception of overall sexual functioning and sexual arousal, all variables that improved at post-treatment (e.g., engagement in sexual activities, satisfaction derived from sexual activities, overall satisfaction with sexual relationship, degree to which breast cancer negatively impacts sexual relationship) were maintained after three months. As previously noted, while moderate and large effect sizes were maintained at 3-month follow-up for many of the variables, lower effect size magnitudes at follow-up point towards a trend of treatment gains being lost over time. Two couples shared that they had lost some of the momentum gained during the intervention, with one couple citing the female partner's subsequent surgeries as the primary reason for this, and a second couple admitting to having fallen back into their old patterns. Correspondingly, some couples

expressed that they would have benefitted from a booster session as a way to support their continued efforts to improve their sexual relationship.

The outcomes of this study are similar to those interventions from which this current intervention was adapted (Kalaitzi et al., 2007; Rowland et al., 2009). In their combined brief psychosexual intervention (CBPI), Kalaitzi et al. (2007) found a statistically significant difference between baseline and post-treatment for sexual intercourse frequency, orgasm frequency, and relationship satisfaction. In contrast to the current intervention, which did not yield any significant improvements in depression and anxiety, women who completed the CBPI did report improvements in depression and state anxiety. However, given the proximity of the CBPI's commencement to women's breast surgery, the authors acknowledged that scores in depression and anxiety may have been more reflective of the distress associated with a cancer diagnosis, pending surgery, and fear of death, rather than sexual difficulties. Rowland et al.'s (2009) group-based intervention for women with breast cancer yielded improvements in relationship adjustment, communication, and sexual satisfaction, whereas women in the control group reported declines. The authors noted that intervention effects tended to be general rather than specific. For instance, while general sexual satisfaction improved, the intervention did not yield improvements for specific sexual outcomes such as variety of sexual activities, sexual pain, or the breast cancer's impact on their sex life. While the current intervention yielded similar results with respect to general sexual satisfaction, women and their partners in the current intervention did experience a noteworthy decrease in the degree to which they perceived breast cancer as having negatively impacted their sexual relationship. Although the current study did not include measures on communication, participants' feedback regarding improvements with communication echoed Rowland et al.'s (2009) findings. In contrast to the aforementioned studies, which did not evaluate the impact of the intervention on partners'

sexual experiences, the current study did evaluate this, and improvement in sexual functioning in male partners was found.

The results of this study reinforce the value of interventions designed specifically to improve sexual functioning in couples affected by breast cancer (as opposed to incorporating sexual enhancement as part of broader relationship enhancement programs). In comparison to these more general relationship enhancement interventions, which did not lead to any statistically or clinically significant improvements in sexual functioning (i.e., Scott et al., 2004; Baucom et al., 2009), psychosexual interventions, including the intervention evaluated in this dissertation, were found to improve various sexual outcomes (Decker et al., 2012; Jun et al., 2011; Kalaitzi et al., 2007; Rowland et al., 2009).

eTherapy

The use of eTherapy proved to be a feasible and acceptable mode of delivery for this intervention, as evidenced by high convenience ratings and generally positive participant feedback. From a logistical standpoint, eTherapy was viewed as a convenient and accessible means of receiving psychological support that may not otherwise have been available or accessible. Many couples did not live in the Greater Toronto Area (GTA), and would not have been able to participate in this study were it not for eTherapy. Couples living near or in the GTA expressed similar sentiments, citing scheduling, travel time, and arranging for childcare as barriers to attending in-person therapy. eTherapy also increased flexibility of scheduling, enabling couples to schedule sessions later in the evening than may have been possible for sessions delivered in-office. It is important to note that although many couples cited late evening sessions as an important benefit of this intervention, these same couples expressed that they would likely not have been able to attend late evening sessions that were offered in-office due to the abovementioned challenges. By eliminating the burden of traveling to an office or

hospital, participants also described feeling more engaged and present in session, as well as with each other after the session.

These findings have important implications for the use of eTherapy not only in the recruitment and retention of participants in intervention studies, but in the provision of clinical services. In addition to reducing geographic disparities, eTherapy eliminates the added costs of transportation, parking, and childcare associated with office-based treatment. These logistical considerations may have additional relevance for couples therapy, which requires coordination of multiple schedules and additional costs associated with both partners potentially missing work (Doss, Feinburg, Rothman, Roddy, Comer, 2017), and not being able to 'trade off' home responsibilities such as childcare because both partners are engaged in treatment. Correspondingly, a randomized trial evaluating couple and family eTherapy interventions found high treatment retention, client engagement, client-therapist agreement on therapeutic goals and tasks, and client satisfaction (Comer et al., 2017a).

The eTherapy modality evidenced very few technical difficulties, which, when present, caused minimal disruption. Although the use of eTherapy eliminated the need to arrange for childcare, it did create a unique challenge to creating a private and uninterrupted space when children were present in the home. When couples did have children, various strategies were implemented to minimize potential disruptions. Strategies included scheduling sessions when young children were asleep or otherwise occupied, arranging for children to be out of the home during the sessions, and informing children (particularly older children) of prearranged meeting times where parents were not to be disturbed. Arrangements were also made to accommodate possible interruptions during the session, such as informing the facilitator of children's presence with a hand gesture, and/or minimizing the eTherapy application to prevent children from viewing the screen.

The advantages of eTherapy extended beyond increasing accessibility, and enhanced participants' experiences in receiving the intervention. According to participants' feedback, receiving therapy from home created a level of comfort that served to foster an open dialogue that may have been unique to this modality. In many ways, the physical comforts of being in their home environment enhanced participants' comfort levels for engaging in discussions about sex and intimacy. The intervention also created a sense of closeness between partners that otherwise may not have been possible in office-based settings. For instance, many couples were in close physical contact during the sessions, often observed to be cuddling or hugging on a couch or on the bed. Although not explicitly stated by participants, it is also possible that this close physical proximity enhanced their sense of connection during the sessions. Consistent with other studies (e.g., Day & Schneider, 2002), participants also found safety and comfort in the distance and separation (from the facilitator) afforded by this modality, which allowed for more openness and communication, particularly with respect to discussing such intimate and private topics. Given the aforementioned benefits, the potential advantages of eTherapy over in-person sexual counselling warrant further investigation.

Not only did the online modality possibly benefit the couple bond, it may also have enhanced their relationship with the facilitator. In a review of the literature on therapeutic alliance in videoconferencing psychotherapy, Simpson and Reid (2014) identified various elements of eTherapy that may contribute to this. For instance, many eTherapy clients report that the increased sense of control and personal space they feel in eTherapy enhances the therapeutic alliance. There is also evidence to suggest that clients are more active in eTherapy than in office-based therapy, with a number of studies reporting higher levels of participation, spontaneity, trust, and disinhibition, which has been attributed to feeling less intimidated and safer to openly discuss feelings and difficulties (Day & Scheider, 2002; Simpson & Reid,

2014). While a few participants indicated that office-based sessions would have been ideal, they were nonetheless satisfied with the remote delivery. Moreover, participants reported that eTherapy felt personal and was comparable to in-person therapy. Although therapeutic alliance was not formally measured, participants' qualitative feedback was indicative of a strong therapeutic alliance. This feedback was consistent with Simpson & Reid's (2014) findings that eTherapy can "facilitate the transmission of warmth and the development of deeper level emotions and attachment" (p. 239) comparable to in-person therapy. Not only is the alliance in eTherapy shown to be more similar to than different from office-based therapy (Comer et al., 2017; Simpson & Reid, 2014), there is evidence to suggest that therapeutic outcomes are also similar. For instance, in a study comparing the process and outcomes of office-based, eTherapy, and telephone-based Cognitive Behavioural Therapy, Day and Schneider (2002) found that similarities across modalities were more apparent than their differences. Moreover, many of the differences reported by participants favoured the distance-based modalities over office-based therapy, as evidenced by higher participant satisfaction scores. Notably absent were any differences in therapeutic outcomes based on modality (Day & Schneider, 2002).

Research has shown that stigma is a significant predictor of seeking out mental health services, and that higher self-stigma reduces the likelihood of seeking out support (Lannin, Vogel, Brenner, Abraham, & Heath, 2016). Men are also more reluctant than women when it comes to pursuing in-person couples therapy (Doss, Atkins, & Christensen, 2003). Correspondingly, online therapy has been found to reduce the stigma associated with face-to face couples interventions, including sex therapy. The findings of the current study highlight the utility of considering eTherapy as a viable modality for the delivery of psychological services, and may be particularly relevant to the provision of couples-based interventions and

interventions that address sensitive topics that may be perceived as taboo. Thus, not only did the eTherapy modality of this intervention prove to be feasible, it may have in fact *increased* its feasibility.

Clinical and Research Implications

The current intervention protocol was based on empirical research pertaining to the sexual difficulties and needs of women and couples affected by breast cancer (Henson, 2002; Karabulut, & Erci, 2009; Tan et al., 2002). It integrated elements previously identified as critical to the treatment of sexual dysfunction in couples affected by breast cancer including sex therapy, partner support and communication skills, along with discussions of body image and the cancer experience (Carroll et al., 2016; Taylor et al., 2011). The conceptual framework was also informed by theoretical underpinnings of Acceptance and Commitment Therapy (ACT) (Hayes et al., 1999) and the Physical Pleasure-Relational Intimacy Model of Sexual Motivation (PRISM) (Beck et al., 2013), which served to facilitate an openness to and exploration of modified and/or alternative expressions of sexuality. In addition to supporting the aforementioned treatment components, the findings of this study led to the emergence of considerations that researchers and clinicians may find useful in the development and implementation psychosexual interventions and in the provision of eTherapy.

Renegotiating definitions of sexual (dys)function.

A particular strength of this intervention, as expressed by participants, was the broad-based and gradual approach to improving sexual functioning. Although the primary aim was to ameliorate sexual difficulties, the current intervention placed less emphasis on traditional or biomedical models of sexual response (i.e., Masters & Johnson, 1966; Whipple, & Brash-McGreer, 1997) that tend to prioritize desire, arousal, and orgasm as the defining features of sexual functioning. It also placed less emphasis on what has been described as the "coital

imperative" (McPhillips, Braun, & Gavey, 2001), which "positions sex as a physiologically driven act, and heterosexual penis-vagina intercourse as 'natural' or 'real' sex, with other forms of sexual activity deemed to be preliminary 'foreplay,' an optional extra, or simply a substitute if the 'real thing' is not possible" (p. 455). Rather, our approach to improving sexual functioning and satisfaction was more in line with the nonlinear model of sexual response (Basson et al., 2004), which incorporates the importance of emotional intimacy, relationship satisfaction, and sexual stimuli. For example, couples were encouraged to engage in alternative and/or additional forms of physical intimacy such as hand holding, kissing and cuddling, non-sexual touching and caressing, etc. In addition, it emphasized all forms of sexual expression and activities, including but not limited to intercourse, oral sex, manual stimulation or mutual masturbation, and sexual touching or caressing, as equally important components of the sexual experience. Accordingly, even in the absence of improvements in "traditional" constructs of sexual response, couples rated their sexual relationship as more satisfying. In fact, couples' satisfaction with their sexual relationship yielded the largest effect sizes at both time points, and was strongly emphasized in their qualitative feedback regarding the benefits of this intervention.

Following a comprehensive review of the sexual health concerns and associated treatment options for female cancer survivors, Sears, Robinson and Walker (2018) highlighted the importance of incorporating a broader definition of sexual activity into investigations of sexual dysfunction. Despite evidence that interventions that teach techniques aimed at improving sexual functioning and enjoyment in a broader sense tend to report greater sexual outcomes, these interventions are somewhat limited (Latini, Hart, Coon, & Knight, 2009). As described by Reese, Keefe, Somers, and Abernethy (2010), interventions designed to address sexual difficulties in cancer patients and survivors tend to focus on the alleviation of sexual

"dysfunction" (i.e., female sexual arousal disorder, erectile dysfunction), and often neglect broader issues related to sexuality and intimacy. Although difficulties associated with the sexual response cycle should certainly not be overlooked, the findings of this study reinforce the importance of broadening our approach to the assessment and treatment of sexual functioning, and encouraging couples with sexual difficulties to do the same.

Enhancing acceptance and flexibility.

The integration of ACT (Hayes et al., 1999) and the PRISM model (Beck et al., 2013) represents a novel contribution to the treatment of sexual dysfunction in breast cancer survivors. Support for incorporating ACT principles into this intervention emerged in the early stages of treatment, as many couples expressed their dissatisfaction with their post-cancer sexual relationship (including women's dissatisfaction with their altered bodies), along with their frustration and discouragement at their inability and/or failed attempts to resume what they defined as a "normal" sex life. Consequently, many couples also reported an avoidance or cessation of sexual activities and interactions, including conversations about sex, in order to minimize their feelings of frustration or discouragement.

Following the clinical interview and introduction of the program, it was emphasized that the goal of this intervention was not to have couples resume the sex life they had before breast cancer diagnosis and treatment. Rather, the goal of this program was to help couples rebuild a mutually satisfying sexual relationship in the context of post-cancer changes, and emphasized the role of acceptance as a first step to achieving this. Couples were encouraged to identify the adverse experiences and challenges that contributed to their sexual difficulties (i.e., physical pain and discomfort, decreased desire and arousal, difficulty achieving orgasm, vaginal dryness, body image issues, etc.), and the impact these had on their sexual relationship. Acceptance played a particularly large role in this intervention, whereby couples were

encouraged to accept these changes and limitations, adjust their expectations, and adapt their sexual activities accordingly. Drawing upon the ACT principle of 'values-based living', couples were then guided through a collaborative exploration of alternative sexual expressions and activities that were in line with their pleasure and relational values.

This exploration was facilitated using the PRISM model matrix, whereby each member of the dyad was asked to rate the degree to which they value physical pleasure and relational intimacy (i.e., closeness and connection), with the goal of increasing each partner's understanding of their own and their partner's sexual needs and values. For example, in addition to placing high value on relational intimacy, individuals were asked to consider *what* specific elements of their sexual relationship contributed to their sense of closeness. Common responses included the giving and receiving of pleasure, being naked with their partner, enjoying alone time together, and post-coital cuddling or "pillow talk". Similarly, individuals were asked to identify what elements of their sexual relationship they found physically pleasurable. It was reinforced that couples could in fact achieve many of these goals in the context of their altered sexuality, and were encouraged to explore modified or alternative ways of achieving these goals. For example, couples who enjoyed being naked together might be encouraged to take a bath or shower together; couples who enjoyed close physical contact might be encouraged to engage in sensual massage; couples who valued quality time together might be encouraged to schedule date nights together. Couples were also encouraged to approach rather than avoid sexual activities and interactions, which involved talking about and planning sexual activities, sharing initiation for sex, acknowledging the potential physical or emotional discomfort in doing so, and providing couples with psychoeducation and strategies for problem solving in this regard.

The integration of ACT principles into this intervention was supported by the literature that shows evidence for the use of ACT to enhance couples' relationship and sexual satisfaction, and improve quality of life in cancer patients (Arabnejad, et al., 2014; Buhrman et al., 2013; Feros, et al., 2013; Nezhad & Shameli, 2017; Peterson et al., 2009). Greater pain acceptance in women with provoked vestibulodynia (pain in the entrance of the vagina) has been associated with a decrease in self-reported pain during intercourse, lower anxiety and depression, improved sexual functioning, and increased sexual satisfaction; greater pain acceptance in women also improved sexual satisfaction in their male partners (Boerner & Rosen, 2015). The authors also posited that women's acceptance of pain can lead to increased motivation to engage in sexual activity and more adaptive coping, which subsequently directs attention away from pain and towards pleasurable aspects of the sexual experience, thus resulting in less subjective pain. The authors defined acceptance as an openness to experiencing pain and giving up futile efforts to control pain, combined with a pursuit of a satisfying sex life despite having persistent localized pain. This definition of acceptance is relevant to women who experience cancer related sexual difficulties, which is often the result of pain and discomfort. Accordingly, in the current study, couples' acceptance of their altered sexuality played an important role in decreasing the degree to which they rated breast cancer as having adversely affected their sexual relationship, and in couples' willingness to engage in sexual exploration and problem solving.

As described by McCracken and Eccleston (2003), acceptance requires a degree of psychological flexibility in acknowledging and integrating sensory, emotional, and cognitive experiences that are present in the context of pain or discomfort, while allowing for the integration of new information and experiences. Although the authors discuss flexibility specifically in the context of reducing physical pain, the importance of flexibility is easily

applied to addressing sexual difficulties. There is evidence to support the importance of flexibility in couples and individuals experiencing sexual difficulties following cancer treatment. For example, a primary area of intervention in a telephone-based program for physical intimacy and sexual concerns in colorectal cancer focused on identifying and challenging overly negative and inflexible sexually related cognitions, and broadening couples' repertoires for sexual and non-sexual intimacy-enhancing activities (Reese et al., 2014). In addition to exploring sexual values, the PRISM model highlights the importance of acceptance, flexibility, and persistence for the successful renegotiation of post-cancer sexuality (Beck et al., 2013). In the context of the PRISM model, flexibility is defined as "the willingness to modify one's actions and reactions in the service of maintaining a satisfying sexual relationship" (p. 1643), such that couples must be willing to modify old ways of having sex and experiment with new sexual activities and sexual scripts.

The PRISM model's approach to flexibility is congruent with Reese et al.'s (2010) model for coping with sexual dysfunction in chronic illness, which they then adapted to help individuals and couples cope with post-cancer sexual concerns. The model of flexible coping highlights two domains that can be altered to be more flexible in response to sexual concerns: 1) definition of sexual function and activity, and 2) the centrality of sexual function and activity (i.e., how critical sexual function and activity are to an individual's self-concept). According to this model, individuals with inflexible views of sexual functioning and activity experience higher levels of distress, and avoid sexual intimacy when they are unable to engage in activities that reflect their definition of sexual function (i.e., sexual intercourse). Conversely, individuals with more flexible definitions of sexual functioning tend to have broader views as to what constitutes sexual activity, including sexual intercourse, non-intercourse sexual activities, and non-sexual intimacy activities, are likely to appraise

challenges as being more easily overcome, and cope more successfully with the changes to their sexual relationship.

Consistent with the model of flexible coping, flexibility was encouraged in this intervention by promoting both cognitive shifts (i.e., altering couples' views of sexual functioning and activities) and behavioural shifts (i.e., engaging in new and modified sexual activity). Couples were also encouraged to renegotiate the degree to which sexual function defined their self-concept and their relationship. Accordingly, and especially when couples were no longer able to engage in activities that previously defined their sexual relationship, namely intercourse, couples were encouraged to consider and engage in other non-sexual activities that fostered intimacy and closeness, and that reinforce their relational and sexual identities. In sum, interventions that emphasize sexual enhancement rather than sexual dysfunction have the potential to normalize couples' responses to and experiences with post-cancer sexuality, promote acceptance of sexual changes and associated experiences, encourage flexible coping, and ultimately support couples in their pursuit of rebuilding a mutually satisfying sex life that is in line with their sexual needs and values.

Promoting relational and approach-based goals.

As described in an earlier section of this dissertation, couples who engage in sex primarily for relational intimacy are more resilient to sexual changes than couples motivated primarily by sexual pleasure (Beck et al., 2013; Beck & Robinson, 2015). That is, couples who are motivated by their desire for closeness and connection adjust better to their altered sexuality. In addition to couple resiliency, there is some literature describing the influence of sexual motivation and goals on sexual behaviours and outcomes. For instance, drawing upon research on communal relationships (Clark & Mills, 2012) and approach-avoidance theories of motivation (Gable & Impett, 2012), Muise and colleagues (2012) sought to understand the

relationship between sexual motivation/goals and sexual desire in couples who are in a long-term relationship. The authors found that couples with higher levels of sexual communal strength (e.g., those motivated to meet a romantic partner's sexual needs) were more likely to engage in sexual interactions for approach goals (e.g., to obtain positive outcomes), and reported higher levels of daily sexual desire than those motivated to meet their personal sexual needs. In their later work, Muise and Impett (2015) found that variations in sexual communal strength also predicted the quality of romantic relationships. Specifically, they found that individuals with high sexual communal strength are perceived by their partners as more sexually responsive, and that these partners feel more satisfied with and committed to their relationship.

As described in the literature, expressing gratitude to a partner (Lambert, Clark, Durtschi, Fincham, & Graham, 2010) and engaging in self-disclosure (Clark & Mills, 2010) both promote communal strength. Accordingly, Muise and colleagues (2012) posited that expressions of gratitude in relation to sex, along with disclosures of sexual wants, needs, and desires, could also promote sexual communal strength in romantic relationships. Although enhancing relational motivation and sexual communal strength was not an explicit goal of this intervention, it is reasonable to assume that conversations led by the PRSIM model matrix (and throughout the intervention), along with the exercises and strategies introduced in each session, fostered couples' relational and approach-based sexual goals. Correspondingly, while objective measures of sexual desire (SFQ-desire) did not improve, participants' expressed desire and enthusiasm to engage in behaviours that served to re-establish their relationship as sexual partners were apparent throughout the intervention and in their subjective feedback, which likely contributed to their increased satisfaction with the sexual relationship.

Facilitating open and effective communication about sex and cancer.

Facilitating open and effective communication, particularly about the sexual relationship, was an integral part of this intervention, and was implemented as early as the first session. Many couples expressed that they had not previously talked about their sexual relationship and difficulties, or that previous conversations had not led to successful resolutions and, in some instances, increased their distress. In fact, for many couples, the initial session was the first opportunity they had had to openly discuss their sexual relationship. Over the course of the intervention, couples were encouraged and received coaching to speak more openly about sex, including the impact of breast cancer on their sex life, as well as their fears, likes/dislikes, needs, goals, etc. As highlighted in participants' feedback, having a safe platform for discussion was considered to be an especially helpful aspect of the program and played a key role in couples' navigation of post-cancer sexuality.

Participants also identified the communication skills building exercise as an important component of the intervention, which helped to facilitate open dialogue, understanding, and empathy. In addition to practicing the exercise, many couples reported spontaneous shifts in their day to day conversations. The decision to incorporate communication skills in the intervention was deliberate, and modeled on previous couples-based interventions that included at least one session on communication as part of the intervention (Caroll et al., 2016; Taylor et al., 2011). Consistent with Deker et al.'s findings (2012), introducing communication skills early on in the program provided a strong foundation that helped couples discuss sensitive matters about sex and breast cancer both within and outside of session. Open communication also played an important role in couples' exploration of and experimentation with new or adapted expressions of sexual intimacy. For instance, communication was part of the sensate focusing homework, whereby couples were encouraged to share their thoughts/feelings during the exercises, and also debrief about their experiences afterwards.

Effective communication has been associated with better dyadic adjustment to sexual changes following breast cancer, and the effectiveness to which couples communicate about sex has been found to influence sexual satisfaction (Delamater, Hyde, & Fong, 2008; MacNeil & Byers, 2009; Montesi, Fauber, Gordon, & Heimberg, 2010; Yoo, Bartle-Haring, Day, & Gangamma, 2014). Scott et al. (2004) also found good communication to have a positive impact on women's sexual-self schema, body image, and perceived partner acceptance. The relationship between communication and sexual satisfaction is not unique to couples affected by breast cancer. For instance, a review of marital intimacy-enhancing interventions among married individuals found that improvements in couples' communication skills typically led to increased sexual intimacy (Kardan-Souraki, Hamzehgardeshi, Asadpour, Mohammadpour, & Khani, 2015). Greater dyadic sexual communication was also associated with increased sexual functioning and satisfaction in women with provoked vestibulodynia and their male partners (Rancourt, Rosen, Bergeron, & Nealis, 2016). As described above, open and effective communication is imperative when it comes to the renegotiation of sex after cancer, and should be considered an essential component of any psychosexual intervention.

Accounting for couple characteristics.

Couple characteristics should be taken into consideration when providing couples-based psychosexual interventions and evaluating these, particularly with respect to relationship distress and engagement. Although baseline relationship quality and adjustment scores suggested that most couples who enrolled in this study were not experiencing any undue relationship distress prior to commencing the intervention, scores for some participants were suggestive of heightened distress. Correspondingly, as the intervention was carried out, some couples' relationship dysfunction made it difficult to intervene effectively around sexual issues. Common examples of relationship dysfunction included one or both partner's

unhappiness or dissatisfaction with their spouse, unresolved emotional injuries or relationship ruptures, and ongoing conflict related to prior or current relationship stressors (e.g., cancer treatment, parenting disagreements). Fortunately, the manual design allowed for some flexibility and tailoring to couples' expressed needs and difficulties; and although the primary aim of this intervention was to enhance sexual intimacy, enhancing emotional intimacy and closeness was an important stepping stone to achieving this. Correspondingly, accommodations were at times made to spend more time focusing on strengthening emotional intimacy in couples with higher levels of relationship dysfunction. Based on the results of this intervention, including couples' feedback, this flexibility did not come at the expense of sexual outcomes; to the contrary, it was viewed as a strength. In fact, in one of the final sessions, a couple whose relationship dysfunction was especially apparent, and had clearly contributed to their sexual dysfunction, was excited to share that they had had sex for the first time after almost six years.

Although not formally assessed, variations in participants' levels of engagement also became evident as the sessions progressed, with low levels of couple and/or individual engagement creating an additional barrier to addressing sexual issues. Participants observed as having lower levels of engagement were less inclined to participate in session discussions and/or less active in homework planning and completion. A variety of factors could potentially have contributed to this lack of engagement including motivation, discomfort with sexuality, personality traits, etc.

Although limited, there is a growing body of literature regarding couples' engagement in online interventions, including couple engagement styles and challenges, as well strategies to maximize engagement. In a study of couple engagement in *Couplelinks*, a therapist facilitated, asynchronous, online intervention for couples with breast cancer (Fergus et al.,

2015), Ianakieva and colleagues (2019) identified four distinct couple types with varying levels of engagement. "Keen" couples were most engaged in the intervention and appeared to be intrinsically motivated to participate. "Compliant" couples completed the program quickly but were less enthusiastic about the exercises. "Apologetic" couples enjoyed and were committed to the intervention, but had difficulty staying on track. "Straggling" couples were the least engaged in the intervention.

Clinical trials evaluating eTherapy interventions for couples and health related issues (versus asynchronous, self-directed online programs such as *Couplelinks*) have generally found high levels of engagement with these modalities (Comer et al., 2017a, 2017b), likely due to their similarities with in-person interventions. In addition to individual factors, several couple characteristics have been found to predict engagement. For example, Biesen & Doss (2013) found that couple agreement of relationship problems predicted greater engagement in the therapeutic process (including having attended more sessions and/or completed the full course of therapy) and more positive treatment outcomes. Conversely, the differential involvement of each member of the dyad has been identified as a challenge to couple engagement (Carter, Fergus, Ahmad, McLeod, & Stephen, 2015). Couple agreement on problems has important implications in couples-based sexual interventions, where members of the dyad could experience their sexual problems as different. Although couples in the current intervention were not overly discordant in describing their sexual problems and goals, occasional differences between partners emerged. For example, while a male partner would identify sexual frequency as a goal for therapy, his spouse might emphasize body image and/or sexual pleasure as an area of intervention. This example also highlights partners' potential lack of awareness regarding the impact of breast cancer on a woman's body (Fergus et al., 2015), and how this relates to their sexual relationship. Consistent with Carter et al. (2015), several male

spouses in the present intervention cited a desire to support their partner as a primary motivation for participation. It was anticipated that partners' motivation and/or lack of awareness could have influenced their engagement in the intervention; as such, the goal of supporting the *relationship* was emphasized throughout the intervention.

In addition to highlighting challenges to engagement, several recommendations for enhancing engagement emerged from the *Couplelinks* intervention. In their synthesized model of engagement promotion (consisting of rational and empirical models), Ianakieva, Fergus, Ahmad, Pos, & Pereira (2016), identified elements considered to be vital to promoting couples' intervention engagement. In the rational model, the authors identified several techniques including fostering a positive attitude toward the program; providing structure; focusing on positive experiences rather than problems; tailoring program content and feedback to each couple; acknowledging the program's demands and time commitments; engaging both partners equally and evenly; as well as conveying genuine interest, concern, and availability. The empirical model emphasized techniques for developing and maintaining the relationship between the couple and the facilitator (e.g., validating experiences and feelings, expressing concern for the couple), the couple and the intervention (e.g., clarifying module aims, encouraging accountability), and between partners within each couple (e.g., accentuating couple strengths, building mutual understanding). Future studies may benefit from the inclusion of measures that assess engagement and/or motivation in order to better understand the degree to which they influence therapeutic processes and outcomes. This information could also help to identify couples who are most motivated to receive sexual counseling, address issues with motivation prior to commencing the intervention, and integrate strategies to maximize engagement.

Instilling confidence and comfort.

Participants' feedback regarding their experiences with the facilitator highlight clinician characteristics that may contribute to the effective delivery of psychosexual interventions. Not surprisingly, participants cited characteristics traditionally associated with a strong working alliance (i.e., empathy, genuineness, unconditional positive regard, collaboration of goals and tasks, etc.) (Rogers, 1942; Simpson & Reid, 2014; Wampold, 2011), as having contributed to their positive experience in this intervention. Participants also cited clinical characteristics and processes identified in the literature as necessary for maintaining a strong working alliance in the context of couples therapy, and spoke about the ways in which the facilitator connected with the dyad and understood the relationship. As described in Rait (2000), therapists must develop and manage multiple alliances when working with couples, including an alliance with each member of the dyad, with the couple as a unit, and between each member of the dyad (e.g., the couple's alliance). Couples therapists must also adopt a conceptual framework that accounts for the complexity of interactions among three people, and view of dyadic exchanges in the context of this three-person "triangle." Finally, Rait (2000) emphasises the importance of recognizing and responding to the influences exerted by the dyad (i.e., the couples emotional process) on the therapeutic process. Similarly, Garfield (2004) identified navigating multiple alliances, avoiding loyalty conflicts by maintaining focus on the couple's overall relationship problems, and prioritizing marital issues over individual symptoms as important clinical considerations for the provision of couples therapy. This third consideration may be especially relevant for couples seeking therapy to address difficulties coping with one partner's altered health. In the current intervention, several couples initially attributed their sexual problems to the changes in the female partner's sexual functioning, which, in addition to women viewing themselves as 'the problem to be fixed' and subsequently blaming themselves, had the

potential to shift the focus from the dyad to one individual. In order to mitigate these potential challenges, couples' difficulties were conceptualized in a way that focused on the burden that the illness placed on the sexual relationship.

While it is presumed that clinicians interested in the evaluation and provision of couples-based psychosexual interventions will be competent in these fields, it is also recommended that providers be informed and knowledgeable with respect to unique challenges experienced by specific health populations. Participants appreciated having a facilitator who understood the ways in which breast cancer affects sexuality. In addition to their confidence in the facilitator's skill set, participants commented on the facilitator's style and how it created a comfortable environment. Specifically, the use of levity, and the ability to work with couples' styles, language, and preferences were highlighted as having contributed to the ease in which sensitive or taboo topics were discussed.

Minimizing the challenges of eTherapy.

The findings of this study support the use of eTherapy as a feasible and acceptable mode of delivery in the provision of couples-based psychosexual interventions. As described above, eTherapy enhanced participants' comfort and overall experience of participating in this study. Participants highlighted the flexibility, convenience, and comforts afforded by this modality as having contributed to their positive experience. Notwithstanding participants' positive feedback, the use of eTherapy did pose some challenges for the facilitator, whereby some of the benefits identified by participants were experienced by the facilitator as potential barriers to engagement. There were various ways that the online modality may have at times contributed to disengagement. For example, although participants appreciated the flexibility with respect to session scheduling, late cancelations and/or delays were not uncommon, with some couples canceling the day of and sometimes minutes before the start of session, or

postponing the session by up to 60 minutes (typically due to one partner being delayed at work). Although the online modality created a safe distance to discuss sensitive topics, this distance may also have reduced couples' accountability for maintaining appointments or cancelling in a timely manner. Late night sessions were cited as a particularly beneficial aspect of this modality, allowing couples to schedule sessions after work hours and/or after children had gone to sleep. In many instances, sessions started as one member of the dyad was arriving from work, which occasionally caused delays settling in to session due to the spouses briefly debriefing about their day or being preoccupied with work-related issues. In some instances, participants' fatigue appeared to affect their attention and engagement in the session, with some participants becoming detached as the session progressed or feeling rushed to get to bed. Finally, although participants appreciated the at-home comforts associated with eTherapy, these "comforts" occasionally distracted participants from being fully engaged. For example, sessions scheduled immediately after work or close to dinner time occasionally resulted in participants' snacking or eating dinner during session. Participants also took more bathroom breaks than might be typical for in-person therapy. In rare instances, participants inspected or answered their phones when it rang, particularly when this was on a landline. Finally, although steps were taken to account for children's interruptions, these interruptions also briefly distracted from the conversation at hand. Although these challenges have not been extensively explored in the literature, there is some evidence to suggest that the flexibility and convenience afforded by eTherapy could prompt more casual interactions and behaviours (Drum and Littleton, 2014) than would normally occur in office-based settings. For example, time-related boundary issues encountered in face-to-face therapy (e.g., early or late arrivals, extension of sessions, holding sessions at odd or inappropriate hours) may be more likely in eTherapy due to "flexibility of the medium, the perception of convenience for both parties, and the potential

for a less regulated/[less structured] work environment" (Drum and Littleton, 2014, p.311). The authors also cautioned against environmental stimuli that could distract from therapeutic interactions and processes. Thus, the less formal environment established by eTherapy may have contributed to participants' taking more liberties that they would in a more formal office setting.

Although the aforementioned conveniences and comforts were identified as benefits by participants, the examples described above highlight the ways in which eTherapy could create potential barriers to therapeutic engagement. Accordingly, these challenges and possible solutions warrant further discussion. Many of these challenges could be minimized by setting expectations that are analogous to in-person therapy including i) pro-active discussions about potential barriers to engagement; ii) requesting that clients silence their phones; iii) creating a work-therapy transition routine at the beginning of session (i.e., brief meditation exercises); iv) establishing and reviewing cancelation policies; v) discussing late cancelation patterns and how they might be resolved; and vi) addressing potential distractions as they arise. Given that prospective clients may be attracted to eTherapy due to the availability of after-hours sessions, clinicians should be cognisant of how this might impact a client's attention and engagement, and address these issues accordingly; this could include changing the session time. While research-clinicians may be inclined to make accommodations in the service of participant retention, those working in private practice or hospital settings may prefer to establish more structured expectations and boundaries. Regardless of the therapeutic milieu, steps should be taken to maximize engagement, while also allowing for some flexibility in the face of unanticipated and/or unavoidable challenges. Carter et al. (2015) developed several principles and guidelines for therapeutic facilitation of online interventions including collaboratively developing a timeline, encouraging open dialogue, creating a virtual therapeutic space,

encouraging structured flexibility, engaging both members of the couple, reinforcing new learning, and managing emotional content.

Study Limitations

Notwithstanding the clinical significance of these results, there were limitations that need to be considered when interpreting the findings. A small sample size is an obvious limitation of this study, which limits the generalizability of the findings. Firstly, a small sample size reduces power and increases the possibility Type 2 errors. It also places limitations on the type of analyses that can be conducted. Given the small sample size, and the increased probability of Type 2 errors, the impact of the current intervention was evaluated by using effect sizes. Although effect sizes estimated from a small sample are less accurate than data obtained from a large sample, the calculation of 95% confidence intervals (CI) increased the rigour of this study (Lee, 2016), such that a 95% CI represents a 5% alpha error rate for the corresponding effect size.

It is important to emphasize that the recruitment challenges encountered in this study, along with the associated small sample size, should not be misconstrued as a lack of need or demand for psychosexual interventions. To the contrary, many participants expressed their gratitude for this resource, and described how the intervention filled a treatment gap and provided a type of support that was notably absent for couples affected by breast cancer. Accordingly, recruitment challenges were more likely reflective of the systemic barriers within the health care system, the implications of which are described below. Initial recruitment efforts for the current study were focused on direct referrals from health care providers in a hospital setting; however, given the challenges encountered in this regard, targeting clinicians (e.g., physicians and nurses) as a primary referral source may not have been the most effective approach – particularly given the absence of a formal sexual counselling clinic at the host

hospital. As described in an earlier section of this dissertation, constraints on clinic time, that sex may not be at the forefront of clinicians' priorities, along with clinicians' personal discomfort in broaching this topic with patients, likely contributed to recruitment challenges in a hospital setting. Intervention studies relying on hospitals for recruitment are also more likely to reach patients who are in active treatment, for whom sexuality may likely not be a focus or priority. While the fact that several couples were successfully recruited in a hospital setting should not be overlooked, advertising the current intervention as a sexuality and intimacy enhancement program may have created a barrier to uptake, with prospective participants feeling reticent to participate in a relational-psychological versus biomedical psychosocial intervention. Accordingly, recruitment efforts in hospital settings would likely benefit from advertising the study in such a way that highlights the physical health and/or biomedical benefits of the intervention (i.e., as a sexual health and/or sexual function intervention rather than as an intimacy intervention per se) - which a broader range of patients may have found more palatable and relevant to their difficulties. Given the successful and almost immediate uptake associated with later recruitment attempts via social media (with four couples self-referring to the study within approximately one month after posting advertisements on social media sites of breast cancer organizations), this would be a recommended recruitment strategy for sexuality-related interventions targeting cancer survivors in the future. Promoting similar interventions via social media may also be particularly relevant to a younger generation of women, who are more likely to be interested in, and concerned with, sexual health and functioning.

Given the small sample size, the findings also do not reflect the full range of demographic characteristics, contexts, or backgrounds of breast cancer survivors. For instance, the average age at the time of diagnosis for women in this study was 43 years old (range 33–55

years). Women aged 50-60 represent the largest group of women diagnosed with breast cancer, at 51%. The second largest group is women over the age of 70, representing 32% of breast cancer diagnoses. Only 17% of breast cancers are diagnosed in women under 50, with women under the age of 40 representing approximately 5% of diagnoses (Rethink Breast Cancer, 2018). In the current study, the sample consisted mostly of women under the age of 50 (65%), including four women under the age of 40. None of the women in the sample were over the age of 70. A number of factors could have contributed to this bias. Over half of the couples in this study were self-referred in response to recruitment flyers posted on the social media pages (e.g., Facebook) of breast cancer organisations. Although statistics regarding social media use are not available for Canada, an American review found that 77% of individuals aged 30-49, 51% of those aged 50-64, and 35% of those aged 65+ currently use Facebook (Topolovec-Vranic, & Natarajan, 2016). In addition to being underrepresented in social media, these statistics could also reflect older individuals' discomfort with technology, and their subsequent reluctance to participate in eTherapy. Increasing age has also been linked to a decreased interest in sex, as well as a decrease in the importance placed on sex (Gott & Hinchliff, 2003; Taylor & Gosney, 2011), which could also account for the lack of representation of older individuals in this sample. Consistent with previous research, the lack of representation may also reflect the reticence of health care providers to discuss sexuality with older patients and the reticence of older individuals to seek support for sexual problems (Gott & Hinchliff, 2003; Taylor & Gosney, 2011).

The sample also comprised mostly of individuals who self-identified as Caucasian (75%), which limits the cultural representation of this sample. The lack of cultural representation is consistent with previous couples-based intimacy enhancement interventions (Fergus et al., 2014; Reese et al., 2014, Robertson et al., 2016). Because same-sex couples

were excluded from this pilot study, it is also unclear as to whether they would benefit from this intervention. Despite the multiple avenues and strategies employed in the promotion and recruitment for this study, only 18 couples were enrolled over the course of a three-year recruitment period, with 15 couples ultimately commencing the intervention. Participant recruitment is routinely identified as one of the common challenges associated with intervention studies for cancer survivors; these challenges are amplified when recruiting for couples-based interventions and interventions that focus on sexuality (Hagedoorn et al., 2015; Friedman et al., 2009; Sears et al., 2003; Stanton et al., 2013; Reese et al., 2018). Although cultural minorities are underrepresented in cancer research, the literature pertaining to the relationship between sociodemographics and enrolment is mixed. While some studies have not found any sociodemographic differences between enrollers and non-enrollers (Byrne, Tannenbaum, Glück, Hurley & Antoni, 2014; Christie, Meyerowitz, Stanton, Rowland, & Ganz,, 2013; Reese et al., 2018), there is evidence to suggest that age, cultural and ethnic background, and education do influence enrollment in psychosocial trials for cancer and other illnesses (Ford et al., 2008; Sears et al., 2003; Pakilit, Kahn, Petersen, Abraham, Greendale, & Ganz, 2001; Sateren et al., 2002; Shavers, Lynch, & Burmeister, 2002; Helgeson, Cohon, Shultz, & Yasko, 2000; Hutchins, Unger, Crowley, Coltman, & Albain, 1999). While the degree to which socio-demographic variables influenced enrolment in this study is unknown, the lack of representation with respect to age and cultural backgrounds could reflect the discomfort in patients and physicians alike to broach the topic of sexuality. Correspondingly, this sample may represent couples that were more comfortable discussing their sexual difficulties and thus more willing to pursue sexual counseling. Although moderate and strong effect sizes support the preliminary effectiveness of this intervention, the small sample size and

demographic homogeneity limit the degree to which these results can be generalized. Future trials should attempt to recruit a larger sample with a broader demographic profile.

Another limitation of the current study was the absence of a control or comparison group. This study was a one sample, repeated measures design, which makes it difficult to ascribe couples' improvements in sexual functioning to the intervention itself or to other factors. However, given that couples often experience sexual difficulties for at least three years following diagnosis and treatment (Ganz et al., 1996), combined with wide range of post-treatment status for women in this study (range 0.25–6 years post-treatment), it is not unreasonable to assume that improvements were, at least in part, attributed to the intervention rather than the passage of time. Nevertheless, it will be important to replicate this pattern of results in the future using randomized controlled studies.

Another limitation of this study is that a single individual was responsible for the design, facilitation, and evaluation of this intervention, which has the potential to bias the outcomes of this study. Allegiance bias is defined as the belief in the superiority of an intervention and the validity of the theory of change associated the intervention (Leykin & DeRubeis, 2009). Although allegiance bias is identified as an area of concern in randomized control trials comparing the efficacy of two (or more) treatment modalities (e.g., CBT versus EFT), and would not have an impact on single armed pilot studies, it does bring to attention the importance of acknowledging potential biases associated with dual researcher-clinician roles. It is worth noting, however, that multiple steps were taken to minimize potential bias. First, the statistical analysis model was selected in consultation with a statistical consultant in order to conduct a stringent evaluation of the psychosexual intervention that would not inflate its effects. Second, post-treatment interviews were conducted by third parties who were not involved in the design or delivery of the intervention, or in the analysis of the data. The

interview protocols were also designed in such a manner that afforded participants the opportunity to comment on the positive *and* negative aspects of the intervention in order to provide an objective evaluation of its feasibly, acceptability, and impact. Third, qualitative content analysis was deliberately selected due to its systematic and rule-based techniques in order to describe, code, and categorize data in the most objective way possible (Forman & Damschroder, 2007). Accordingly, the themes generated in the analysis were based on participants' descriptions of their experiences, and these were taken at face value rather than on interpretive or theory-based themes, which strengthened the objectivity of the qualitative results. Finally, qualitative data interpretation was undertaken by the author in consultation with the dissertation supervisor in order to validate the coding scheme, emerging themes, and their interrelationships. This approach, which is referred to as consensual validation, further ensured that the themes generated did not represent the idiosyncratic perspective of one interpreter. In the future, larger studies that utilize multiple therapists to administer the intervention, and that minimize dual researcher-clinician roles and clinician effects, would further reduce potential biases, improve the study's replicability, and strengthen the evidence for the effectiveness of this intervention protocol.

Future Directions

The results of this pilot study suggest that a six-session, couples-based psychosexual intervention may help to alleviate sexual difficulties in couples affected by breast cancer. The triangulated method yielding both quantitative and qualitative results increased confidence that this intervention was effective at improving couples' sexual relationships in multiple sexual domains. The intervention had a noteworthy impact on couples' overall satisfaction with their sexual relationship, and the degree to which they perceived breast cancer as having negatively impacted their sexual relationship. The results also suggest that eTherapy is a feasible mode of

delivery, and may be especially beneficial in the provision of therapies that may not otherwise be readily available and/or easily accessible. Given the challenges to recruitment and retention in psycho-oncology intervention research, and especially in those involving couples, future studies should consider online modalities as a way to mitigate these challenges.

While the results of this study provide preliminary evidence regarding the effectiveness of this intervention for improving sexual functioning and satisfaction for couples facing breast cancer, a decrease or absence in effect at 3-month follow-up suggest that these gains may not be retained in the long-term. As previously described, the loss of gains likely reflected couples' challenges in maintaining the behavioural changes with respect to their sexual relationship (i.e., increased engagement in sexual activities) established over the course of the intervention. Although the final session sought to maximize these gains by addressing potential challenges to maintaining the momentum gained during the intervention, future iterations of this intervention could be strengthened by additional sessions, which may provide couples with additional strategies and time to establish long lasting behavioural changes. Areas for improvement in this regard could include expanding session three (Let's Talk about Sex: Exploring Sexual Values) and session five (Sexual Enhancement and Problem Solving) into two separate sessions each (e.g., Let's Talk about Sex Part 1 and 2, Sexual Enhancement Part 1 and 2). In addition to exploring couples' sexual values in greater depth, along with providing more space for couples to explore sexual challenges and associated strategies, expanding the program from six to eight sessions has the potential to increase couples' engagement in sexual problem solving and exploration, and establish a stronger momentum for continued change moving forward. As suggested by several couples, the addition of a booster session (i.e., at 6 weeks post-treatment) would also serve as a check-in and opportunity to address any challenges and barriers to maintaining a satisfying sexual relationship.

In addition to providing preliminary evidence regarding the effectiveness of this intervention in alleviating sexual difficulties, this study put forth a number of considerations that contribute to advancement of psychosexual interventions for breast cancer survivors and their partners. Most notably, interventions would benefit from adopting a flexible approach to addressing sexual dysfunction that moves beyond the medical model. Correspondingly, interventions that broaden the approach to the assessment and treatment of sexual functioning; encourage acceptance and flexibility with respect to the range of physical and psychological changes that adversely impact sexual identities and relationships following breast cancer; promote relational and approach-based goals; facilitate effective communication; and instil confidence and comfort, are likely to be most effective in assisting couples renegotiate and navigate their post-cancer sexual relationship. Psychosexual interventions should also allow for some flexibility with respect to focus and content, such that it can be modified to address couples' specific difficulties and needs, and account for couple characteristics that influence the sexual relationship (e.g., couple distress). Researchers and clinicians should also consider the viability of eTherapy as a feasible and acceptable modality for the delivery psychological services, which may be particularly relevant for couples and certain health populations where ease of access is particularly important. In addition to increasing the availability and accessibility of services, eTherapy may enhance clients' comfort and experience in receiving psychological services. Notwithstanding these benefits, researchers and clinicians should consider the potential challenges or barriers associated with eTherapy, and how these could be minimized. Because the proposed considerations are based on a small, uncontrolled study of one psychosexual intervention, they should be considered preliminary, and warrant further investigation. Nonetheless, we hope that they will provide some guidance in the design and delivery of future interventions.

The current study fills a notable gap in the support available to couples experiencing sexual difficulties following breast cancer. Future studies should use a large scale, randomized control trial design with longer follow-up in order to evaluate the lasting effects of this intervention. The benefits of more intensive interventions (e.g., 8-10 sessions) that include a booster session also warrant further investigation. There is also potential for this intervention to be adapted for other health populations including but not limited to different cancer diagnoses and stages, chronic illness, and physical disabilities that require couples to alter their sexual activity in order to accommodate physiological, mechanical, and physical limitations.

Despite the overwhelming evidence regarding the negative impact of breast cancer on women's sexual identities and relationships (Male et al., 2016), these issues remain under-addressed by health care providers, and interventions designed to specifically address problems with sexuality and sexual relationships in couples affected by breast cancer remain limited. While there is an increasing recognition of sexual health as an integral part of overall health, breast cancer survivors continue to identify sexuality as their top unmet need related to cancer care (Pauwels, Charlier, De Bourdeaudhuij, Lechner, & Van Hoof, 2013). By continuing to empirically evaluate sexual counseling interventions for breast cancer survivors and their partners, it is hoped that women's sexuality will be considered a priority in breast cancer survivorship, and that information, support, and psychosexual interventions will become more readily available, and ultimately, have a regular presence in cancer care settings.

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Appendices

Appendix A: Introductory Script and Screening Questionnaire

Briefly introduce the study, including goals, format, responsibilities, enrolment process, duration, privacy, etc. Indicate that further details will be provided in the consent form. Invite questions.

For Women:

1. Have you been diagnosed with breast cancer? When?
2. What treatments have you had (or are you currently undergoing)?
3. Have you been told that you have advanced or metastatic disease? (not eligible)
4. Can you briefly describe the current difficulties you are experiencing in your sexual and intimate relationship as a result of breast cancer? (*Assess for sexual problems caused by BC and/or pre-existing issues; Assess for relationship distress; ask about current or past couples' therapy*). Note: Couples ineligible if they are currently receiving or plan to receive couples therapy during the course of the study.
5. Are you in a committed relationship of one year or more with a male partner?
6. Have you had any mental health problems in the past? Please describe.
7. Have you had any problems with drug/alcohol abuse? Please describe.
8. Do you have any difficulty with written or spoken English?
9. Are you comfortable using a computer for accessing the internet, email, video conferencing (i.e., SKYPE) and the like?
10. Do you have a computer and internet access in your home? Do you have more than one computer?

For partners:

1. Can you briefly describe the current difficulties you are experiencing in your sexual and intimate relationship? (*Assess for sexual problems caused by BC and/or pre-existing issues; Assess for relationship distress; ask about current or past couples' therapy*).
2. Have you had any mental health problems in the past? Please describe.
3. Have you had any problems with drug/alcohol abuse? Please describe.
4. Do you have any difficulty with written or spoken English?
5. Are you comfortable using a computer for accessing the internet, email and the like?

Appendix B: Baseline Measures

Demographic Questionnaire

Breast Cancer Prevention Trial (BCPT) Symptom Checklist (Females only)

In Your Own Words – Open ended questions about sexual difficulties

Program Expectancy Questionnaire

Demographic Questionnaire

1. Age _____ 2. DOB _____

3. How do you describe yourself? (*Please highlight one number*).

___ White/Caucasian
___ Black/African-Canadian
__ Asian/Pacific Islander
___ First Nations/Aboriginal/Native Canadian
___ Latino/Hispanic/Mexican-Canadian
___ Middle Eastern/Arab/Indian
___ Other (please specify):_____

4. Please describe your current relationship:
___ married
___ common law
___ not living together

How many years have you been in this relationship? _____

5. Do/Does you/ your partner have any health issues, or other concerns that may prevent him/you from engaging in sexual activities? *(Please describe)* YES NO

6. How much school did you complete?

___Grade school or less ___Some college
___Some high school or technical school ___ College graduate
___High school or technical school graduate ___ Graduate or professional degree

7. What is your approximate annual combined household income?

___ Less than $20,000 ___ $20,000-39,000 ___ More than $80,000
___ $40,000-59,000 ___ $60,000-79,000

8. Are you now working at a paying job?
___Yes, full time ___Yes, part-time
___No, but looking for a job ___No, retired

9. (Women only) When were you diagnosed with breast cancer? _____

10. (Women Only) What treatments have you had for breast cancer? (*Please highlight **YES** or **NO** for **<u>every</u>** item and fill in the month/year during which therapy was started).*

Mastectomy (surgery to remove the breast)	YES	NO	Date _____
Lumpectomy (surgery to remove a malignant lump)	YES	NO	Date _____
External Beam Radiation	YES	NO	Date _____
Chemotherapy	YES	NO	Date _____
Expectant management (Watchful Waiting)	YES	NO	Date _____
Other (please specify:	YES	NO	Date _____

11. Why did you agree to participate in this project? _____

Breast Cancer Prevention Trial (BCPT) Symptom Checklist (Females only)

We are interested in knowing how much you have been bothered by any of the following problems during the **PAST 4 WEEKS.** *(Highlight one number on each line. If you do not have the problem, highlight "not at all".)*

During the **past 4 weeks,** how much were you bothered by:	Not at all	Slightly	Moder-ately	Quite a bit	Extreme ly
1. Hot flashes……	0	1	2	3	4
2. Nausea……...	0	1	2	3	4
3. Vomiting……	0	1	2	3	4
4. Difficulty with bladder control when Laughing or crying……	0	1	2	3	4
5. Difficulty with bladder control at other times…….....	0	1	2	3	4
6. Vaginal dryness.……	0	1	2	3	4
7. Pain with intercourse..……...……	0	1	2	3	4
8. General aches and pains..……..…….	0	1	2	3	4
9. Joint pains……...……...……	0	1	2	3	4
10. Muscle stiffness……..……	0	1	2	3	4
11. Weight gain…….	0	1	2	3	4
12. Unhappy with the appearance of my body...…….....	0	1	2	3	4
13. Forgetfulness...…… ……	0	1	2	3	4
14. Night sweats...……	0	1	2	3	4
15. Difficulty concentrating...……...	0	1	2	3	4
16. Easily distracted...…… ……...	0	1	2	3	4
17. Arm swelling (lymphedema)...…….……	0	1	2	3	4
18. Decreased range of motion in arm on surgery side...…..	0	1	2	3	4

In your own words…

1) Currently, what are your current struggles around sex? Please describe.

2) What do you think your partner struggles with?

Program Expectancy Questionnaire

By the end of the program, how much improvement in your sexual intimacy do you really *feel* will occur?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Appendix C: Outcome Measures

Sexual Function Questionnaire (SFQ)

Revised Dyadic Adjustment Scale (R-DAS)

Maudsley Marital Questionnaire (MMQ)

Centre for Epidemiological Studies Depression Scale (CES-D)

Generalized Anxiety Disorder Assessment (GAD-7)

The following are a list of questionnaires designed to assess your current functioning in a variety of areas relevant to this study. Please read them carefully and answer as honest as possibly. We also ask that you complete the questionnaires independently, without discussing these with your partner.

Sexual Function Questionnaire (SFQ)

These next questions are sensitive and personal. They are very important in understanding how your medical illness or treatment affects yourself and your body. Some questions ask about your own experiences, thoughts, and feelings, while others ask about how treatment has affected your intimate relationships. Please answer each question honestly and accurately. *Be assured that your responses are completely confidential.*

---

1. Have you been sexually active in the **PAST YEAR** (alone or with a partner)?
   0 = NO
   1 = YES

2. Have you been sexually active in the **PAST MONTH** (alone or with a partner)?
   0 = NO
   1 = YES (***Please skip to Question 4***)

3. I am not sexually active because: (Highlight as many items as apply)
   0 = I have never been sexually active.
   1 = I am too tired.
   2 = I am not interested.
   3 = I have a physical problem that makes sexual relations difficult or uncomfortable.
   4 = My partner is not interested.
   5 = My partner is too tired.
   6 = My partner has a physical problem that makes sexual relations difficult or uncomfortable.
   7 = I do not have a partner at this time.
   8 = Other (please describe)

4. In the PAST MONTH, how frequently have you had sexual thoughts, urges, fantasies, or erotic dreams? *(Please highlight the one item that is closest to your experience)*
   0 = Not at all
   1 = Once
   2 = 2 or 3 times
   3 = Once a week
   4 = 2 or 3 times per week
   5 = Once a day
   6 = More than once a day

5. Using the scale below, how frequently have you felt an **interest or desire to engage in** the following specific activities in the PAST MONTH?

(This question is about your thoughts, fantasies or wishes, <u>not</u> about how you feel during sexual activity.) (For each item, please highlight one number that is closest to your experience):

		Not at all	Once	2 to 3 times	Once a week	2 to 3 times per week	Once a day	More than once a day
a.	Dreams or fantasy	0	1	2	3	4	5	6
b.	Masturbation	0	1	2	3	4	5	6
c.	Touching, hugging, holding, kissing	0	1	2	3	4	5	6
d.	Petting and foreplay	0	1	2	3	4	5	6
e.	Vaginal intercourse	0	1	2	3	4	5	6
f.	Other sexual activity *please specify:*	0	1	2	3	4	5	6

6. Using the scale below, how frequently have you become **aroused by** the following sexual activity in the PAST MONTH? *(By arousal, we mean the physical and emotional responses in your body and mind that tell you that you are feeling sexual)*:

		Not at all	Once	2 to 3 times	Once a week	2 to 3 times per week	Once a day	More than once a day
a.	Dreams or fantasy	0	1	2	3	4	5	6
b.	Masturbation	0	1	2	3	4	5	6
c.	Touching, hugging, holding, kissing	0	1	2	3	4	5	6
d.	Petting and foreplay	0	1	2	3	4	5	6
e.	Vaginal intercourse	0	1	2	3	4	5	6
f.	Other sexual activity *please specify:*	0	1	2	3	4	5	6

7. In the PAST MONTH, have you **felt pleasure** from any sexual activity?
   0 = I have had no sexual activity in the past month
   1 = I have not felt any pleasure
   2 = Seldom, less than 25% of the time
   3 = Sometimes, about 50% of the time
   4 = Usually, about 75% of the time
   5 = Always felt pleasure

8. Using the scale below, how frequently have you **engaged in** the following sexual activity in the PAST MONTH?

		Not at all	Once	2 to 3 times	Once a week	2 to 3 times per week	Once a day	More than once a day
a.	Dreams or fantasy	0	1	2	3	4	5	6
b.	Masturbation	0	1	2	3	4	5	6
c.	Touching, hugging, holding, kissing	0	1	2	3	4	5	6
d.	Petting and foreplay	0	1	2	3	4	5	6
e.	Masturbation with a partner	0	1	2	3	4	5	6
f.	Vaginal intercourse	0	1	2	3	4	5	6
g.	Other sexual activity *please specify:*	0	1	2	3	4	5	6

9. In the PAST MONTH, how often have you **reached orgasm** (climax) during sexual activity?
   0 = I have had no sexual activity in the last month.
   1 = I have not experienced orgasm.
   2 = Seldom, less than 25% of the time.
   3 = Sometimes, about 50% of the time.
   4 = Usually, about 75% of the time..
   5 = I always experienced orgasm

9a. When you have **orgasms** (climax), how **intense** have they been in the PAST MONTH?

0 = I have had no sexual activity in the last month.
1 = I have had no orgasms in the last month.
2 = My orgasms were **very mild**.
3 = My orgasms were **fairly mild**.
4 = My orgasms were **fairly strong**.
5 = My orgasms were **very strong**.

9b. How **easy or difficult** has it been for you to have **orgasms** (climax) in the PAST MONTH?

1 = I have had no sexual activity in the last month.
2 = I have had no orgasms in the last month.
3 = It was **very difficult** to have orgasms; it took a long time and a lot of concentration.
3 = It was **fairly difficult**; it took a while.
4 = It was **fairly easy**.
5 = It was **very easy**.

10. How frequently in the PAST MONTH have you had the problems listed below? **ALSO**, MARK THE BOX IN THE LAST COLUMN if the problem stops or reduces your sexual activity.

	Not at all	**Seldom, less than 25% of the time**	**Sometimes, about 50% of the time**	**Usually, about 75% of the time**	**Always**	**MARK THE BOX IF THE PROBLEM STOPS OR REDUCES SEXUAL ACTIVITY**
a. Lack of wetness in your vagina as you became sexually excited	1	2	3	4	5	☐
b. Lack of sexual desire	1	2	3	4	5	☐
c. Lack of sexual arousal	1	2	3	4	5	☐
d. Difficulty reaching orgasm	1	2	3	4	5	☐
e. Vaginal tightness	1	2	3	4	5	☐
f. Painful penetration or intercourse	1	2	3	4	5	☐

g. Vaginal bleeding or irritation after penetration or intercourse	1	2	3	4	5	☐
h. Sharp pain inside or outside your vagina	1	2	3	4	5	☐
i. Increased sensitivity of your skin to intimate touching	1	2	3	4	5	☐
j. Other problem with sexuality; *Please specify*:	1	2	3	4	5	☐

11. Please rate how **interested you have been in sexual thoughts, feelings, or actions** in the PAST MONTH by **circling a number** from 0 to 10 (0=not at all interested, 10=extremely interested).

0 1 2 3 4 5 6 7 8 9 10
Not at all Interested Extremely Interested

12. Please rate the extent to which **sexual activity has been satisfying** for you in the PAST MONTH by circling a number from 0 to 10 (0=not at all satisfied, 10=extremely satisfied).

0 1 2 3 4 5 6 7 8 9 10
Not at all satisfying Extremely Satisfying

13. How often did the following factors **influence your sexual activity** in the PAST MONTH?

		I have not had a partner	Not at all	Seldom, less than 25% of the time	Sometimes, about 50% of the time	Usually, about 75% of the time	Always
a.	My own health	0	1	2	3	4	5
b.	My partner's health	0	1	2	3	4	5
c.	Conflict in my relationship	0	1	2	3	4	5
d.	Other *please specify:*		1	2	3	4	5

14. Are you currently in a married or partner relationship that could be sexual?
    0 = NO, I do not have a possible partner
    1 = YES, I am married or have a partner, and we HAVE been sexually active this past Year
    2 = YES, I am married or have a partner, but we HAVE NOT been sexually active this past year

15. How frequently have you been able to communicate your sexual desires or preferences to your partner in the PAST MONTH?
    0 = I have not had a partner
    1 = I was always able to communicate my desires or preferences
    2 = Usually, about 75% of the time
    3 = Sometimes, about 50% of the time
    4 = Seldom, less than 25% of the time
    5 = I have been unable to communicate my desires or preferences

16. Overall, how satisfied have you been with your sexual relationship with your partner?
    0 = I have not had a partner
    1 = Very satisfied
    2 = Somewhat satisfied
    3 = Neither satisfied nor dissatisfied
    4 = Somewhat dissatisfied
    5 = Very dissatisfied

17. Overall, how satisfied do you think your partner has been with your sexual relationship?
    0 = I have not had a partner
    1 = Very satisfied
    2 = Somewhat satisfied
    3 = Neither satisfied nor dissatisfied
    4 = Somewhat dissatisfied
    5 = Very dissatisfied

18. Please rate how **satisfied you have been with your ability to share warmth and intimacy** with your partner in the PAST MONTH by **circling a number** below from 0 to 10 (0=not at all satisfied, 10=extremely satisfied).

0	1	2	3	4	5	6	7	8	9	10
Not at all Satisfied										Extremely Satisfied

19. Please rate how **comfortable you are with touching, hugging or holding your partner** in the PAST MONTH by circling a number from 0 to 10 (0=not at all comfortable, 10=extremely comfortable).

0 1 2 3 4 5 6 7 8 9 10
Not at all comfortable Extremely Comfortable

20. Please rate how well you think you have **adjusted to changes in your sex life since your illness and treatment** by circling a number from 0 to 10 (0=not at all well, 10=extremely well).

0 1 2 3 4 5 6 7 8 9 10
Not at all well Extremely Well

21. What **impact** has your illness or treatment had on your sex life?
- 1 = My sex life is a lot better than before
- 2 = My sex life is a little better than before
- 3 = My sex life is no different than before
- 4 = My sex life is a little worse than before
- 5 = My sex life is a lot worse than before

22. What impact has your illness or treatment had on your **interest** or **desire** for sex? (*This question is about your thoughts, fantasies or wishes, <u>not</u> about how you feel during sexual activity.)*
- 0 = My interest is stronger
- 1 = My interest is about the same
- 2 = My interest is a little less
- 3 = My interest is somewhat less
- 4 = My interest is a lot less
- 5 = I have lost all of my interest

23. What impact has your illness or treatment had on your **sexual arousal** during sexual activity? *(By arousal, we mean the physical and emotional responses in your body and mind that tell you that you are feeling sexual.)*
- 0 = I am aroused more easily than ever
- 1 = Arousal is about the same
- 2 = It takes longer to get aroused, but the level of arousal is about the same
- 3 = It takes longer to get aroused, and the level of arousal is not as intense
- 4 = It is quite a bit more difficult for me to get aroused
- 5 = I do not seem able to get aroused at all

24. What impact has your illness and treatment had on your **orgasms** during sex?

0 = They are stronger than ever
1 = They are about the same
2 = It takes longer to orgasm, but the intensity is about the same
3 = It takes longer to orgasm, and they are less intense than before the illness and treatment
4 = Since the treatment, I am unable to orgasm
5 = I have never experienced orgasm

25. Is there anything you would like to add about how sex has changed for you **since your/your partner's illness and treatment**? Please describe in the space below. *(Asked at baseline only)*

Revised Dyadic Adjustment Scale (R-DAS)

Most people have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list.

	Almost Always Agree	Always Agree	Occasionally Agree	Frequently Disagree	Almost Always Disagree	Always Disagree
1. Religious matters	5	4	3	2	1	0
2. Demonstrations of affection	5	4	3	2	1	0
3. Making major decisions	5	4	3	2	1	0
4. Sexual relations	5	4	3	2	1	0
5. Conventionality (correct or proper behaviour)	5	4	3	2	1	0
6. Career decisions	5	4	3	2	1	0

	All the time	Most of the time	More often than not	Occasionally	Rarely	Never
7. How often do you discuss or have you considered divorce, separation, or terminating your relationship?	5	4	3	2	1	0
8. How often do you and your partner quarrel?	5	4	3	2	1	0

9. Do you ever regret that you married (or live together?)

5	4	3	2	1	0

10. How often do you and your partner "get on each other's nerves''?

5	4	3	2	1	0

Almost Every Day	**Every Day**	**Occasionally**	**Rarely**	**Never**

11. Do you and your partner engage in outside interests together?

4	3	2	1	0

How often would you say the following events occur between you and your partner?

Never	**Less than once a month**	**Once or twice a month**	**Once or twice a week**	**Once a day**	**More often**
12. Have a stimulating exchange of ideas					
0	1	2	3	4	5
13. Work together on a project					
0	1	2	3	4	5
14. Calmly discuss something					
0	1	2	3	4	5

Maudsley Marital Questionnaire (MMQ)

This scale is designed to measure the quality of your current marriage/committed relationship. Please indicate the first response that you feel accurately reflects the status of your current relationship. Please be as honest as possible.

Respond to each question by circling the number (between 0 and 8) that best fits with your personal situation. There are no wrong answers.

---

1. How much are you committed to this marriage/relationship?

0 1 2 3 4 5 6 7 8

No thought of separation ever — Brink of separation or divorce

2. Does life with your partner bring you satisfaction (*not* including sexual side of the relationship)?

0 1 2 3 4 5 6 7 8

Completely satisfactory — Completely unsatisfactory

3. Do you feel your partner is a good spouse?

0 1 2 3 4 5 6 7 8

Pretty good — Very poor

4. Are you satisfied with the leisure activities that you both share in, for example: gardening, entertainment, trips, etc. – or would you like more shared activities?

0 1 2 3 4 5 6 7 8

Quite satisfied — Completely dissatisfied, no point in trying

5. How much tension, coolness, quarrelling, nagging or violence is there within the marriage/relationship?

0 1 2 3 4 5 6 7 8

Quite smooth, warm relationship — Intolerable quarrelling and/or violence

6. When you have arguments, are you able to reach a compromise?

0	1	2	3	4	5	6	7	8
Complete agreement or compromise								Arguments seem to drag on forever

7. Can you let your partner know your true feelings?

0	1	2	3	4	5	6	7	8
Frank & open with partner								Conceal all emotions all the time

8. Do you get enough warmth and understanding from your partner?

0	1	2	3	4	5	6	7	8
Quite satisfied								Feel a deep need for understanding & warmth

9. Does your partner take his/her full share of responsibility?

0	1	2	3	4	5	6	7	8
Partner is reasonably responsible								Partner is totally irresponsible & untrustworthy

10. Is your partner attractive to you as a person (not physical attraction)?

0	1	2	3	4	5	6	7	8
Very attractive								Unattractive

Centre for Epidemiological Studies Depression Scale (CES-D)

INSTRUCTIONS: For each statement, please place a mark in the column that best describes how you have been feeling *in the past week*.

		Rarely or none of the time (less than 1 day)	Some or a little of the time (1 – 2 days)	Occasionally or a moderate amount of the time (3 – 4 days)	Most or all of the time (5 – 7 days)
1.	I was bothered by things that usually don't bother me.				
2.	I did not feel like eating; my appetite was poor.				
3.	I felt that I could not shake off the blues, even with the help from family or friends.				
4.	I felt that I was just as good as other people.				
5.	I had trouble keeping my mind on what I was doing.				
6.	I felt depressed.				
7.	I felt that everything I did was an effort.				

8.	I felt hopeful about the future.				
9.	I thought my life had been a failure.				
10.	I felt fearful.				
11.	My sleep was restless.				
12.	I was happy.				
13.	I talked less than usual.				
14.	I felt lonely.				
15.	People were unfriendly.				
		Rarely or none of the time (less than 1 day)	Some or a little of the time (1 – 2 days)	Occasionally or a moderate amount of the time (3 – 4 days)	Most or all of the time (5 – 7 days)
16.	I enjoyed life.				
17.	I had crying spells.				
18.	I felt sad.				
19.	I felt that people dislike me.				
20.	I could not get “going”.				

Generalized Anxiety Disorder Assessment (GAD-7)

Over the last 2 weeks, how often have you been bothered by any of the following problems? Read each item carefully, and highlight your response.

	Not at all	Several days	More than half the days	Nearly every day
a. Feeling nervous, anxious, or on edge	0	1	2	3
b. Not being able to stop or control worrying	0	1	2	3
c. Worrying too much about different things	0	1	2	3
d. Trouble relaxing	0	1	2	3
e. Being so restless that it's hard to sit still	0	1	2	3
f. Becoming easily annoyed or irritable	0	1	2	3
g. Feeling afraid as if something awful might happen	0	1	2	3

Appendix D: Treatment Satisfaction Questionnaire - Post-Treatment Only (T1)

We are asking for your assistance in providing feedback about the Online Sexual Counseling Program you recently completed. Your responses will be kept strictly confidential, and your name will not be associated with any of your comments.

Program Evaluation:

Overall, how satisfied were you with the Online Sexual Counseling program?

1	2	3	4	5
Very Dissatisfied	Dissatisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very Satisfied

Please elaborate:

_____
_____
_____
_____
_____
_____

Overall, I found the program to be convenient:

1	2	3	4	5
Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree

Please elaborate:

_____
_____
_____
_____

What did you like best about the program?

_____
_____
_____
_____
_____

What did you like least about the program?

_____
_____
_____
_____
_____

What was the most valuable thing you learned?

_____
_____
_____
_____
_____

Were there any components (e.g., weekly exercises or from individual sessions) that you did not find informative or helpful? If so, please specify:

_____
_____
_____
_____
_____

Are there any ways that we could improve this program? Please be specific about what you would like to see changed:

_____
_____
_____
_____
_____

General:

Have you ever participated in any other couples counselling or educational programs (e.g., premarital classes)? Yes _____ No _____

If yes, how did this program compare to the one(s) in which you previously participated?

_____
_____
_____
_____
_____

Any additional comments?

_____
_____
_____
_____-

Thank you very much for your feedback

Appendix E: Description of Sexual Functioning Questionnaire (SFQ) Subscales

SFQ Total:	Total mean score
SFQ-interest:	Interest/desire/engaged in sexual dreams or fantasy
SFQ-desire:	Desire for sexual and/or non-sexual contact (e.g., kissing, hugging, petting, foreplay intercourse)
SFQ-arousal:	Aroused by sexual and/or non-sexual contact (e.g., kissing, hugging, petting, foreplay intercourse)
SFQ-satisfaction:	Pleasure or satisfaction derived from any form of sexual activity
SFQ-problems:	Physical problems that interfere with sex (e.g. males – difficulty achieving/maintaining an erection; females- vaginal dryness, pain)
SFQ-activity:	Engaged in sexual activity (e.g. petting, foreplay, intercourse)
SFQ-masturbation:	Engaged or desire to engage in masturbation
SFQ-orgasm:	Frequency and easy of orgasms
SFQ-relationship:	Satisfied with sexual relationship, perceived partner's satisfaction
SFQ-cancer impact:	Degree to which cancer is perceived to have negatively affected the sexual relationship

Appendix F: Post-Treatment Interview Protocol

Introductory Remarks: [do not have to be read verbatim]

"Thank you for taking the time to speak with me today. This interview should take approximately 45 minutes to complete and, with your permission, will be audio-recorded. We are conducting these interviews to supplement the questionnaires you completed since this is such a new program and there is a lot to be learned from participants about how they found the individual sessions and the exercises. The information we obtain through these interviews will be grouped together and used to inform and improve the program in the future. This interview will be used for this purpose only and will be confidential."

*May I audio record this interview? [*If yes] *Great. If at any point you would like us to pause, or for me to pause the recorder – please let me know.*

Start official recording: State "*Today is [***date and time***], this is [***interviewer's name***] and I am speaking with [***participants' first names***]."*

Remember:

- Have participants elaborate on their words (e.g., Participant: "I found exercise 1 most enjoyable"; Interviewer may ask: "What about it was enjoyable")
- After one partner responds to a question, invite the other partner to comment as well.
- The questions overlap and participants may have already answered the question in a previous response, so it may not be necessary to ask every question.

So my first question…..

Please share with me your experience of the Sexual Counselling Program

- What was it like to take part in this program?
- What were your expectations going into the program? (probe re: whether these were met).
- In what ways was the program helpful to you? How so?
- Are there any parts of the program you found to be less helpful?
- What did you like most? What did you like least?
- What would you have liked more of? Less of?
- Is there anything about this program that you did not expect? Please specify.
- In what way did the program fall short of your expectations?
- Please share what you felt was missing from the program. What would you have hoped to focus on more?
- Can you think of any modifications that we could make to some of the modules in order for them to be more relevant to your relationship?
- What, if any, were the challenges to participation?

Please share with me your experience of the homework completed between sessions

- Looking back on the program and the homework, what exercises stand out to you?
- What was your preferred exercise? Please elaborate.
- Which exercise did you like the least? Please elaborate.
- What, if any, were the challenges to completing the homework?

Please share with me your experience with Kim Cullen, your counsellor

- What was it like working with Kim?
- What did you like about her style/approach? What did you dislike?
- To what degree did Kim make you feel comfortable talking about sex and intimacy?
- Is there anything else she could have done to make you feel more supported?
- What other support from her do you think would be beneficial to future participants?

Please share with me your experiences of the online component?

- What was it like to meet with a counsellor via video-conferencing?
- What did you like best about the online format? What did you like least?
- Any challenges/ disadvantages to the online format?
- How do you think therapy delivered via video-conferencing would compare to face-to face counselling?
- What, if anything, could have been gained by meeting with a counsellor face-to-face?

If not addressed, query re: anything specific that might have occurred with this particular dyad

E.g., Did they have scheduling issues? Did they have difficulty completing exercises between sessions? Did they have a problem with a particular module?

Please share with me any other thoughts

- Is there anything else you would like to share with us about your experience in this program? With the counsellor? Or in relation to future directions for the program?

Thank them once again for their participation and valuable feedback.

Appendix G: Session Manual

Session 1: Clinical Interview, Alliance Building

Session 2: Communication Skill Building

Session 3: Let's Talk about Sex. Exploring Sexual Values

Session 4: Psychological and Emotional Impact of Breast Cancer on Sexual Relationships

Session 5: Sexual Enhancement and Problem Solving

Session 6: Consolidation and Moving Forward

Session 1
Clinical Interview, Alliance Building

Session goals

i) Develop therapeutic and couple alliance
ii) History and information gathering
iii) Identify/conceptualize sexual difficulties and goals
iv) Expectation setting

Session Format / Clinical Interview

1) Therapist introduction. Explaining format of today's session. Invite questions.

2) I'd like to hear from you about what prompted you to participate in this intervention so that I can understand more fully about the difficulties that you have identified as problematic in your sexual relationship.

3) Can you tell me about your sex life before breast cancer?
   i) Frequency
   ii) Sexual activities?
   iii) Sexual satisfaction?

4) How has your sexual relationship changed following breast cancer and treatment?
   i) Frequency
   ii) Sexual activities?
   iii) Sexual satisfaction?
   iv) New issues that have come up?
   v) Anything unexpected?

5) What about going through breast cancer has been the most difficult for you with respect to your sexual relationship?
   i) Female (Probe for personal, medical, and relational difficulties)
   ii) Partner

6) To what extent have you discussed these issues with each other?
   i) Do you generally talk about sex?
   ii) Have you in the past?
   iii) What do these conversations look like?
   iv) Do both of you initiate these conversations?
   v) Can you give me an example of a time you had a conversation about sex?

7) Have you done or tried anything to address and of these issues and / or improve your sexual relationship?

i) What have you found helpful?
ii) What have you not found helpful?

8) What kind of changes would you like to see in yourself, your partner, and in your sexual relationship?

9) What are you hoping to learn or gain from this intervention?

10) If you were to look back on this experience and say "This intervention really worked for me?" what would you be doing differently? How would you know we succeeded?

Program Introduction

Introduce the intervention, goals, and brief summary of the sessions.

"The goal of this intervention is not to have couples return to sex as it was before the cancer. In fact, putting pressure on ourselves to do this can make the discomfort and distress associated with sexual changes even worse. Instead, we will work together to learn to talk about these changes, acknowledge them and grieve them, and work towards accepting and embracing a new normal. Remember, DIFFERENT doesn't mean worse!"

Introduce Homework

"Next week we will focus on communication skill building as a way to start talking about sex. For next week, I would like each of you to think about an issue or topic you would like to discuss with your partner about your sexual relationship - perhaps something you have been hesitant to discuss or have already discussed and would like to explore further. This can be something specific to sex or intimacy in general (i.e., spending time together, something that makes you feel closer or further away from your partner, concerns about the changes in your sex life.) I encourage you not to discuss this with your partner."

Wrap Up

Elicit Feedback and Questions

Session 1 Homework/Handout

In session 2, we will focus on communication skill building as a way to start talking about sex. For next week, select an issue or topic you would like to discuss with your partner about your sexual relationship, perhaps something you have been hesitant to discuss or have already discussed and would like to explore further. This can be something specific to sex or intimacy in general. Examples include spending time together, something that makes you feel closer or further away from your partner, concerns about the changes in your sex life, etc. It's up to you! I encourage you not to discuss this with your partner.

Here's a preview for what we'll be doing. One of you will be the **sender**. This is the person who will start the conversation by stating the issue or topic. The other will be the **receiver**, the one listing to the message. This will occur in three steps.

The Receiver's Tasks: After receiving the issue, the 'receiver' will respond in three distinct ways, in sequence:

Mirroring Attempt to reflect back the content of the sender's message. Keep trying until you get it right.

Validating Tell your partner that from *her/his perspective*, the experience being communicated to you makes sense. You see her/his point of view and accept its validity. This doesn't necessarily mean you agree.

Empathizing Develop a mental image of, or reflect the *feelings* the sender is experiencing in the event being described.

You will both take turns as speaker and listener.

Session 2
Communication Skill Building

Session 2 focuses on communication skills building, whereby couples are taught to empathically listen and attend to their partners, to communicate their needs, thoughts, and feelings to their partner, and how to support one another.

Session goals

i) Facilitate and normalize communication about sex and intimacy.
ii) Facilitate empathic communication and listening.
iii) Deepen each partner's understanding of the other.

Check In

Are there any questions or things that came up for you last week? Probe for expansion on or identification of new goals? Probe for any conversations or reflections that occurred throughout the week.

Introduce session goals and format

Note: If the couple are already great communicators, express this to them. Encourage any communication skills the couple has.

"The goal of this session is to help you learn a new communication skill and improve your understanding of your partner and their experience. One of the ways the exercise does this is by helping us to slow down the natural flow of the communication process, so we can better hear our partners. These skills can be used to enhance communication about all topics/issues, but I think it will be helpful in this case because sex not something everyone is used to talking about. The exercise will seem awkward at first, but with practice it can be a very useful tool. Communication is essential when it comes to sex and intimacy. When issues with sex come up, communication is like the bridge back to sex, and we want the bridge to be solid so that we can cross it."

"One of you will be the **speaker**. This is the person who will start the conversation by stating the issue or topic. (Start with female partner). The other will be the **receiver**, the one listing to the message. This will occur in three steps.

Mirroring: You will repeat your partner's statement back to them to confirm that you understanding of the sentiment being expressed. Basically, you can repeat what they said to you in your own words. This can start with things like 'So what I'm hearing you say is that…' Other comments like 'Is that right? Is there more?'

Validating: Offer validation, allowing your partner to hear that they are entitled to her feelings. "It makes sense to me that you would…"

Empathy: Making sure you understand how they are feeling, what is the underlying message here? Are they feeling confused, frustrated, scared, lonely, rejected? This can start with 'From what I understand about you.' Providing empathy not only helps you to better understand what your partner is expressing, but also helps them feel heard and

understood by you. This can help you grow closer and feel more connected.

Walk the couple through the exercise

"Let's get started. Remember, it will feel awkward at first; that's ok and completely normal, this is a new way of communicating. We will go through this slowly, don't worry, I will help walk you through it."

Ask ***speaker*** to state the issue. "Remember to speak from your own experience and describe thoughts and feeling using *I* statements."

Note: If there is time, try the exercise with male partner. If there is not time, suggest the couple start with the male partner as homework and offer to briefly walk the couple through the exercise at the beginning of next session.

Exercise Debrief

i) Ask each partner - What was it like to go through this exercise? (validate difficulties, address any issues of the couple)
ii) What did you learn about the other person or their experience?
iii) Any challenges?
iv) Elicit feedback and questions

Introduction of Sensate Focusing

Explore couple's meaning of sensuality and sexuality.

i) What is sensual touch? What is sexual touch?
ii) How are they different? How are they the same?
iii) Can touch be both sensual AND sexual?

"Sensate focusing is a series of techniques that progress through stages with the goal being not to achieve orgasm, but to have an appreciation of a whole new set of sensual possibilities. Intercourse and orgasm are not the ultimate goal here. Another goal of this exercise is to build trust and intimacy within your relationship, helping you to give and receive pleasure. It emphasizes positive emotions, sensations, and responses, while reducing any negative reactions. The exercise can help overcome any fear of failure that may have existed previously, building a more satisfying sexual relationship in which both partners feel able to ask for what they want and are able to give and receive pleasure."

"Sensate focusing progresses through several stages. The exercises are done in steps over a period of time. Typically, sessions last twenty to sixty minutes, two to three times a week, and spread over six or more weeks. The pace depends on your progress and comfort. Sensate Focusing is not a race to an end. How long you spend doing this is up to you. Do not change stages until both of you are ready."

General Guidelines for Sensate Focusing

- Schedule a time that is suitable for the both of you.
- Turn off phones, television, and eliminate all other sources of distraction.
- Set an environment that is soothing and comfortable; this could include things like soft music, candles, scents you find pleasant, massage oils, etc.
- You can be naked, wear underwear or other comfortable clothing.
- ***If you are the GIVER:*** Take time to explore your partner's body, taking pleasure in experiencing things like different textures and shapes. Try to discover the different types of touch and pressure that your partner finds most enjoyable.
- ***If you are the RECEIVER:*** Remember, arousal is not the goal here (but its ok to get aroused). Rather, focus on the different sensations as your partner explores your body and touches your skin. Be open and communicate what you like and don't like. Use encouraging language like "I like it better when…" and avoid saying things like "Don't…" as this can be discouraging.
- It is helpful to talk about your experiences as giver and receiver after each exercise. Talk about what you enjoyed as giver and receiver. Don't be afraid to talk about something you might like to try.
- During each stage, partners take turns being the giver and the receiver. After 15 minutes (or longer if you like) change roles.

Introduce Stage 1 of Sensate Focusing

Stage 1 involves touching each other's bodies in areas that are NOT sexually stimulating, (no touching of genitals and breasts, or erogenous zones). Intercourse is also not permitted. ***The goal of this stage is to enjoy and become increasingly aware of qualities of your partner's body, including the shape and texture of their skin***. Focus on what you find interesting about your partner's body, not on what you think they may enjoy. Focus on the parts of the body that are normally visible, including face, head, scalp, arms, hands and feet. When you feel ready, include neck, back, buttocks, and legs. Finally, touch the chest, stomach, shoulders, and thighs (avoid the groin and breasts). If you are the receiver, mindfully pay attention to the different sensations of your body. Notice what feels pleasurable, what you feel less comfortable with (try not to label as good or bad), pay attention to any new sensations or any areas of pleasure you may not have noticed before.

Introduce Homework

1) Practice intentional dialog 2-3 times a week. This only needs to take 10-20 minutes. Remind couples to use the Intentional Dialogue Handout as a guide.
2) Practice Sensate Focusing Stage 1, 2-3 times per week.
3) Elicit conversation about motivation to complete homework, possible challenges to completing homework, as well as solutions to potential barriers.
4) In preparation for next session, briefly introduce PRISM model:

PRISM Model for Sexual Motivation
"People have many different motivations for having sex. Two of the main reasons are physical pleasure and relational intimacy (closeness).

"Sex for Pleasure means being motivated for sex because it is physically satisfying, pleasurable, and a form of release. Having sex because it feels good physically. Achieving orgasm is often a part of this.

"Sex for Intimacy/closeness means being motivated to have sex because you enjoy feeling connected and emotionally close to your partner. This involves finding enjoyment in the quality time you are spending together, feeling connected on an emotional level, and a sense of well-being and romance.

"These two concepts are like two different dimensions, and it's possible to value sex for pleasure AND intimacy; they aren't mutually exclusive. Your motivation can be high in both, low in both, or high in one and low in the other.
Present couples with PRISM model (homework/hangout for session 2).
"For next week, I would like you to think about your driving desire for sex and where you fall on the continuum. We will take a look at this next week."

Wrap Up
Elicit and feedback questions.
Identify possible challenges and strategies for completing homework.

Session 2 Homework/Handout

1) INTENTIONAL DIALOGUE

Over the week, ***schedule 3 times*** to practice the intentional dialogue exercise from session two. This can me something spontaneous that comes up for you, something that came up from the session, or something you've wanted to discuss to bring up with your partner. It will help to have the script next to you as a reminder. As the sender, remember to speak from your experience, using "I" language. As the listener you will mirror, validate, and empathize, holding back any reactions you may have. As we discussed, this isn't always easy and remember you can use another intentional dialogue to express your reactions. Take your time, it will feel awkward to slow things down :) Start with a topic that feels neutral/less emotionally charged. Remember, the point is to practice a skill – learning to swim before jumping in the ocean.

Mirroring: you will mirror your partner's statement back to them, to confirm that you understanding of the sentiment being expressed. Basically, you can repeat what they said to you in your own words. This can start with things like "So what I'm hearing you say is that…" Other comments like "Is that right? Is there more?"
Validating: Offer validation, allowing your partner to hear that they are entitled to her feelings. "It makes sense to me that you would…"
Empathy: Making sure you understand how they are feeling, what is the underlying message here? Are they feeling confused, frustrated, scared, lonely, rejected? Providing empathy not only helps you better understand what your partner is expressing, but also helps them feel heard and understood by you. This can help you grow closer and feel more connected. i.e., " From what I understand about you" (or also take what you know about your partner)

2) SENSATE FOCUSING

Schedule 2-3 times during the week to practice **Stage One** of the sensate focusing exercise. Each session can last 30-60 minutes. Start with one partner as receiver and then after 15-20 minutes, switch. See guidelines and helpful tips for sensate focusing below.

STAGE ONE involves touching each other's bodies in areas that are NOT sexually stimulating, (no touching of genitals and breasts). Intercourse is also not allowed. ***The goal of this stage is to enjoy and become increasingly aware of qualities of your partner's body, including the shape and texture of their skin***. Focus on what you find interesting about your partner's body, not on what you think they may enjoy. Focus on the parts of the body that are normally visible, including face, head, scalp, arms, hands and feet. When you feel ready, include neck, back, buttocks, and legs. Finally, touch the chest (for men), stomach, shoulders, and thighs (avoid the groin and chest). If you are the receiver, mindfully pay attention to the different sensations of your body. Notice what feels pleasurable, what you feel less comfortable with (try not to label as good or bad, pay attention to any new sensations or any areas of pleasure you may not have noticed before."

Sensate Focusing

Sensate focusing is a series of techniques that progress through stages with the goal being not to achieve orgasm, but to **have an appreciation of a whole new set of sensual possibilities. Intercourse and orgasm are not the ultimate goals here.** Another goal of this exercise is to **build trust and intimacy** within your relationship, helping you to give and receive pleasure. It **emphasizes positive emotions, sensations, and responses while reducing any negative reactions**. The exercise can help overcome any fear of failure that may have existed previously, building a more satisfying sexual relationship in which both partners feel able to ask for what they want and are able to give and receive pleasure.

Sensate focusing progresses through several stages. The exercises are done in steps over a period of time. Typically, **sessions last thirty to sixty minutes, two to three times a week, and spread over six or more weeks.** The pace depends on your progress and comfort. Sensate Focusing is not a race to an end. How long you spend doing this is up to you. **Do not change stages until both of you are ready.**

General Guidelines

- Schedule a time that is suitable for the both of you
- Turn off phones, television, and eliminate all other sources of distraction
- Set an environment that is soothing and comfortable; this could include things like soft music, candles, scents you find pleasant, massage oils, etc
- You can be naked, wear underwear or other comfortable clothing.
- ***If you are the GIVER:*** Take time to explore your partner's body, taking pleasure in experiencing things like different textures and shapes. Try to discover the different types of touch and pressure that your partner finds most enjoyable.
- ***If you are the RECEIVER:*** Remember, arousal is not the goal here. Rather, focus on the different sensations as your partner explores your body and touches your skin. Be open and communicate what you like and don't like. Use encouraging language like "I like it better when…" and avoid saying things like "Don't…" as this can be discouraging.
- It is helpful to talk about your experiences as giver and receiver after each exercise. Talk about what you enjoyed as giver and receiver. Don't be afraid to talk about something you might like to try.
- During each stage, partners take turns being the giver and the receiver. After 15-30 minutes (or longer if you like) change roles.

3) FOR NEXT WEEK

Using the diagram below, think about your driving desire, motivation and the value you place on sex where you call on the continuum. What is important to you? We will take a look at this next week. Print out a copy and indicate where you fall on the PRISM. Do this without discussing with your partner.

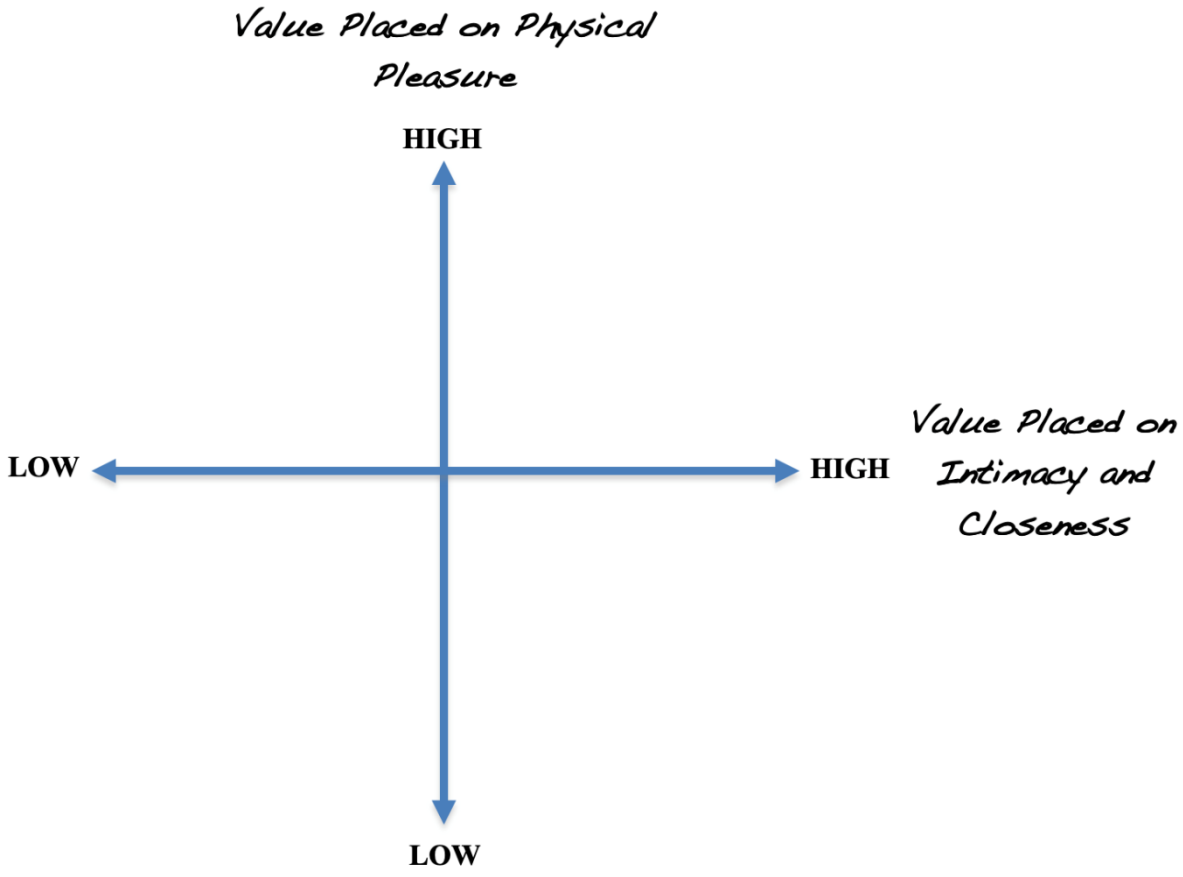
How Do You Value Sex?

People have many different motivations for having sex. Two of the main reasons are physical pleasure and relational intimacy or closeness.

Sex for Pleasure: This means being motivated for sex because it is physically satisfying, pleasurable, and a form of release, because it feels good physically. Achieving orgasm is often a part of this, but doesn't need to be.

Sex for Intimacy: Means being motivated for sex because you enjoy feeling connected and emotionally close to your partner. This Involves finding enjoyment in the quality time you are spending together, feeling connected on an emotional level, involves a sense of well-being and romance.

These two ideas are like two different dimensions, and it's possible to value sex for pleasure **AND** intimacy, they aren't mutually exclusive. **Your motivation can be high in both, low in both, or high in one and low in the other.**



Session 3
Let's Talk about Sex: Exploring Sexual Values

This session will focus on engaging the couple in a dialogue about sex and intimacy, including an exploration of each partner's sexual attitudes, values, and expectations, and to facilitate a dialogue about this.

Session Goals

i) To elicit a conversation of and identify each partner's values regarding sex, pleasure,
intimacy/connection. Highlight/emphasize similarities.
ii) To explore and identify new and/or alternative ways of being sexual and/or intimate that are in line with the couple's values. Focus is on specific behaviours/activities.

Check in and Homework Review

Intentional Dialogue

Did you practice any intentional dialogue over the week? What was it like? Challenges? Questions? Validate awkwardness and unnatural feelings that come up and first. Help couple problem-solve any challenges. Encourage couple to continue with this.

Sensate Focusing

Did you practice any sensate focusing over the week? What was it like? Did you create a sensual environment? What was your experience as giver/receiver? What did you notice? Challenges? Questions?

Explore Sexual Values

Review couple's PRISMs and take stock of where each partner falls on the continuum.

Discussion points:

i) Do you see how this is the expectation for JANE/JOHN?
ii) Is there anything that surprised you about JANE/JOHN's desire?
iii) What do you **VALUE** in your sexual relationship? What is important to you?
iv) For *intimacy/connection* – identify what makes each partner feel connected to the other (this can include things both inside and outside of the bedroom).
v) For *sexual pleasure* – identify what each partner finds physically pleasurable?
vi) ***Discussion Point*:** Based on the values you described above, are there new ways you can think of to achieve these goals?
vii) What are other ways or things you can do to meet those values?
viii) Given each of your motivations/desire what are ways of achieving this?
ix) ASK BOTH PARTNERS FOR EXAMPLES
    i) INTIMACY/CONNECTION GOALS:
    ii) PLEASURE GOALS:

Psychoeducation/Talking Points

- Men often see intimacy and sex as happening together.
- Women often need intimacy *before* sex.
- Characteristics that enhance sexual resiliency:

i) Acceptance: Accepting what you are given. Assessing the situation and developing realistic expectations about your current and future sexual relationship. Fighting against this and trying to get back to the way things were can lead to frustration, resentment, and is emotionally draining. When we can set this frustration aside, we are able to consider alternative ways and solutions to regaining and maintaining sexual relationships.
Acceptance also means acknowledging the grief and how you feel about loss of your old sexual relationship (this can include loss of breasts, loss of certain sexual activities, loss of closeness). It's ok to grieve these things.

ii) Flexibility: This is the willingness and ability to adapt and be flexible. This means being flexible and modifying previous ways of having sex. This requires modifying and experimenting with new ways of sex.

Examples could involve scheduling sex instead of being spontaneous, finding ways to have sex in a comfortable way, and COMMUNICATION.

iii) Persistence: Ability to try again despite difficulties and barriers. Trying things a few times even when they feel new, awkward, uncomfortable. Continuing to try new things. Not giving up because something didn't work.

Discussion Point: What might be some barriers to adopting this new way of approaching sex? What could be some solutions? (i.e., getting information and resources, experimenting and trying new things until you find something that works and is satisfying for both of you. Requires patience, determination, and ability to see your partner's perspective.)

Introduce Homework

1) **Sensate Focusing**

STAGE TWO continues with the type of touch and exploration in stage one, but increases touch options to include breasts and nipples (remember men have nipples too!). ONLY include breasts if you are comfortable with this. Continue to pay attention to the areas of the body from stage one while incorporating these new areas. In addition to breasts and nipples, explore other erogenous zones and areas of sensual pleasure like inner thighs and areas around and close to the genitals. ***The main goal of this stage is to increase each person's pleasure and awareness of each other's responses to different types of stimulation.*** In this stage, the "receiver" can also place their hand over the "giver's" hand in order to show what they find pleasurable in terms of pace and pressure. If one or both of you become aroused this is fine but it is not the aim of the exercise.

2) Practice Intentional Dialogue (2-3) times.

3) Intimacy Wish List

"Based on our discussion, come up with a wish list of things both you and your partner could do to feel closer to and more intimate. Think about this in two ways:

a) What are the day to day things that make you feel closer to your partner. What are those little things that your partner does for you that gives you the 'warm and fuzzies?' (e.g., a foot massage at the end of the day, I love when my partner has coffee ready in the morning, our nightly walks). What are some more "bedroom related" things what would make you feel closer and more intimate (e.g cuddling, pillow talk).

NOTE: *Place emphasis on the day to day activities*.

b) ***What are some things you might like to try or do differently that would feel pleasurable to you.***

Remember to be specific – focus on behaviours and things that are tangible. "So, if you have 'I'd like to feel more supported by my partner,' what would your partner be doing to make you feel more supported? If I was watching the Jane and John movie, what would I be seeing? How would I know that your partner was being supportive of you?"

Wrap Up

Elicit and feedback questions.

Identify possible challenges and strategies for completing homework.

Session 3 Homework/Handout

1) **SENSATE FOCUSING**
Schedule 2-3 times during the week to practice **Stage Two** of the sensate focusing exercise. Each session can last 30-60 minutes. Start with one partner as receiver and then after 15-20 minutes, switch. See guidelines and helpful tips for sensate focusing below.

STAGE TWO continues with the type of touch and exploration in stage one, but increases touch options to include breasts and nipples (remember men have nipples too!). Continue to pay attention to the areas of the body from stage one while incorporating these new areas. In addition to breasts and nipples, explore other erogenous zones and areas of sensual pleasure like inner thighs and areas around and close to the genitals. ***The main goal of this stage is to increase each person's pleasure and awareness of each other's responses to different types of stimulation.*** In this stage, the "receiver" can also place their hand over the "giver's" hand in order to show what they find pleasurable in terms of pace and pressure. If one or both of you become aroused this is fine but it is not the aim of the exercise.

2) Continue practicing the **INTENTIONAL DIALOGUE** (2-3 times a week).

3) INTIMACY WISHLIST
a) Based on our discussion in Session 3, come up with a wish list of things both you and your partner could do to feel closer to and more intimate with one another. Think about this in two ways: What are the day to day things that would make you feel closer to your partner. What are some more "bedroom related" things what would make you feel closer and more intimate. Also, don't forget about the pleasure spectrum: What are some things you might like to try or do differently that would feel pleasurable to you. ***Remember to be specific – focus on behaviors and things that are tangible.***

Session 4
Psychological and Emotional Impact of BC on Sexual Relationships

This session will focus on altered bodies, body image, menopause, sexual attitudes and behaviours, couples' responses to the physical and sexual changes associated with breast cancer, as well as the impact of these changes on their intimacy, sex life, relationship. This session also addresses the impact of cancer and treatment (e.g., cancer is a major life stressor/change) on each partner and the couple. While this session addresses each partner's experience, the focus tends to me more female-centric.

Session Goals:

i) To explore, validate, and normalize the couple's experience of going through breast cancer.
ii) To elicit a conversation between partners regarding the impact of breast cancer and increase the couple's mutual awareness and appreciation of their own, each other's, and collective experience.
iii) To enhance intimacy and connection by facilitating a couple's sense of shared identity, journey, meaning with respect to breast cancer.

Check in and Homework Review

Sensate Focusing
Did you practice any sensate focusing over the week? What was it like? What was your experience as giver/receiver? What was the experience of incorporating breast and erogenous zones. What did you notice? Challenges? Questions? Validate experiences. Address challenges.

Intentional Dialogue
Briefly check in with intentional dialogue. Encourage couples to continue with exercise.

Review Intimacy Wish list
Review each partner's intimacy wish list, with a focus on behaviours that elicit a sense of closeness and connection. Wish list is used to facilitate exploration of solutions and strategies to increasing closeness and intimacy.

Exploring emotional impact of breast cancer.
"*Today's session will focus on the psychological and emotional impact that breast cancer can have on intimacy and sexual relationships. These things can impact couples at all stages of cancer from the initial shock of diagnosis, treatment (anxiety, depression, sex falling on by the waste side due managing cancer and other responsibilities), changes in your body, body image issues, and how we relate and interact with each other. Each of you may have your own struggles, some may be the same, some might be different. Today's session will bring some of these difficulties to light and provide some helpful strategies for addressing some of these."*

Discussion Points: The goal is to identify, normalize, and validate the couple's challenges, which also help guide the psycho-education, solutions, and strategies relevant to each couple.

i) F: How has cancer affected your desire to have sex or be intimate with your partner? (ALL STAGES OF CANCER – diagnosis, treatment, now).
ii) F: What do you think has played a role in this? (Look for physical vs emotional/body image).
iii) F: Do you feel comfortable with how your body looks? Do you see yourself as sexually attractive?
iv) F: Are there any parts of your body that you don't want your partner to touch or see? (Be specific).
v) F: Are there sexual activities you enjoyed before that you worry about not enjoying or being comfortable with now? What are these? (*note: these questions also provide guidance for session 5*)
vi) Do you experience any pain or lack of physical or emotional response with sexual activity?
vii) M: Has your wife's/partner's breast cancer and treatments affect the way you interact with her in any way?
viii) M: What about the way you see her?
ix) Is there anything about your partner or your sexual activities that have changed or that you miss? **(**NORMALIZE and VALIDATE**)**

<u>Psychoeducation about impact of breast cancer and challenges</u>

i) PSYCHOLOGICAL distress that many women experience as a result of breast cancer

- Psychological impact of cancer can occur during all stages of cancer from the initial shock of being diagnosed with breast cancer to worrying about recurrence years after treatment has ended.
- Can lead to overall distress, difficulties coping, depression and anxiety and lower quality of life.
- In general, depression leads to decreased desire, arousal, and ability to achieve orgasm
- Understandably, when you are dealing with all of these issues sex and sexual difficulties may not be at the top of your list of things to address.
- Sex can fall by the wayside, which can leady to challenges of reclaiming sexuality and sexual relationships with their partner once the other issues have been addressed.

ii) Body image

- Even with breast reconstruction breasts aren't what they used to be and this can be difficult for women.
- Body image concerns also stem from other physical changes associated with treatment including hair loss from chemo, weight gain and lowered self-esteem.
- Other things that affect the way you see yourself?
- Partners play an important role in the sexual functioning of women recovering from breast cancer – and so it's important for both partners to communicate their concerns, fears, and experiences.

iii) Detachment of breasts from sexuality

- Breasts are gendered organs in that they often define femininity and can be an essential aspect of female body image.
- Breasts are sexual organs and the daily exposure of breasts during treatment can cause women to be dissociated from their breasts as sexual organs.
- As a result of regular breast exams, regular exposure during radiation therapy, breast really become the focus of the illness and women with breast cancer often describe their breasts as being medicalized during the various stages of treatment.
- *Many women connect that if a person with a white coat enters the room, their first action is to expose their breasts for examination. This CONTRASTS to the usual notion that breasts are a private part of a woman's body that are for the nourishment of babies or are part of sexual play.*
- Tattoo marks left on the chest from radiation are also constant reminder of the cancer and have can long lasting emotional and sexual effects.
- So, breasts become more and more associated with medical procedures and less and less associated with sex

iv) Partner's experience

- Some men may withdraw from making sexual requests in response to their female partner's anxiety, depression, and altered body image.
- Some may withdraw for fear of hurting their partner.
- Some withdraw to avoid feeling rejected if previous attempts to initiate sex have been unsuccessful.
- Some men withdraw so as to avoid pressuring their spouse.
- Others may withdraw because they disturbed by patient's appearance after surgery.

<u>Solutions and Strategies</u>

i) Discussion points

- **F:** What are some things that make you feel good or sexy?
- **F:** What could your partner do to make you feel more attractive/sexy?
- **M:** What are some of the things you find attractive about your wife?
- We discussed this last week, but what could each of you do to feel closer/more intimate/more connected sexually?

ii) Enhancing body image, self-acceptance, confidence

- For women, body image often plays a significant role as a challenge to rebuilding a sexual relationship – often more than physical pain/discomfort (validate that emotional changes should not be minimized and are just as important as physical limitations).

- Many women experience cancer as a violation of a private space, and their body as an area of pain rather than pleasure. In this case, many women become detached from their bodies as a result (like in a sexual assault).
- It is important to explore ways to reconnect with and experience bodies as an area of pleasure, safety, and comfort.
- Do this SLOWLY, can start with a manicure.
- Do things that make you look and feel good:
- Foot massage, facial, bath, relaxing with a scented candles etc
- Clothing – wear fabric that feels good on your skin (like silk or cashmere), colors that make you feel good (both inside and outside the bedroom).
- Do things that help you reconnect with your body:
- Yoga, meditation, take a walk alone, dance, physical activities you used to enjoy.
- Elicit participants' exploration and feedback regarding activities.

iii) Expressing affection (finding your way back to sex)

- Increase efforts to show affection.
- Don't assume that stopping sexual activity means stopping physical affection.
- By the same token, don't assume that physical affection always needs to lead to sex.
- It is especially important to engage in other forms of physical affection when we are not having sex.
- Open and honest communication is key!!! Encourage discussion about boundaries and comfort levels.
- Kiss, cuddle, hold hands, make out, take a bath, be naked, be silly, slow dance in your kitchen.
- Elicit couples' exploration and feedback regarding activities.

iv) Adjusting to changes in sexual relationship

- An important barrier to finding your way back to a satisfying sex life is holding onto the idea that sex has to be what it was before breast cancer and the assumption or belief that different sex means inferior sex.
- This means acknowledging the loss and grief of previous sexual relationships (because it is a loss), but also needing to embrace new experiences.
- Shift from "I will never be the same again" to "life will be different, and I have the resources I need to find "new ways of satisfaction."

Introduce Homework

1) Sensate Focusing

In STAGE THREE, you can gradually include touching of the genitals. Start with breasts and nipples. Don't forget to pay attention to the other parts of the body from stage one and two. Then continue on to the areas around the genitals, including the testicles. Then introduce the genitals themselves, including the clitoris and entrance to the vagina on the woman, and the penis and shaft on the man. You can introduce a teasing technique, which involves manually

stimulating your partner for a while and then taking a break. Intercourse and penetration are not permitted in this stage. Experiment with different sensations, pressure, and speed. You may wish to include lubricants in this stage.

2) **Select three things on your partner's wish list to do for them, or together.** Remember, this is not about keeping score. It is about appreciating each other's efforts, and the things that make you feel closer. You can also make some of these joint efforts if you like.

3) **For next session**, think of a time you felt sexually satisfied and/or connected to your partner. Think about where you were, what you were doing. Was it a romantic evening? An anniversary? What about this particular time made it special for you? Write it down a few sentences. Do this separately. Do not discuss it with one another. We will revisit this next week.

4) Continue practicing the Intentional Dialogue.

Wrap Up
Elicit and feedback questions.
Identify possible challenges and strategies for completing homework.

Session 4 Homework/Handout

1) INTIMACY WISHLIST

Select three things on your partner's wish list to do for them, or together. Remember, this is not about keeping score. It is about appreciating each other's efforts, and the things that make you feel closer. You can also make some of these joint efforts if you like:)

2) SENSATE FOCUSING

Schedule 3 times during the week to practice **Stage Three** of the sensate focusing exercise. Each session can last 30-60 minutes. Start with one partner as receiver and then after 15-20 minutes, switch. See guidelines and helpful tips for sensate focusing below.

In STAGE THREE, you can gradually include touching of the genitals. Start with breasts and nipples. Don't forget to pay attention to the other parts of the body from stage one and two. Then continue on to the areas around the genitals, including the testicles. Then introduce the genitals themselves, including the clitoris and entrance to the vagina on the woman, and the penis and shaft on the man. You can introduce a teasing technique, which involves manually stimulating your partner for a while and then taking a break. Intercourse and penetration are not permitted in this stage. Experiment with different sensations, pressure, and speed. You may wish to include lubricants in this stage. Note: Inquire about difficulties completing sensate focusing exercises, and explore solutions/strategies.

3) FOR NEXT WEEK

Think of a time you felt sexually satisfied and/or connected to your partner. Think about where you were, what you were doing. Was it a romantic evening? An anniversary? What about this particular time made it special for you? Write it down a few sentences. Do this separately. Do not discuss it with one another. We will revisit this next week.

4) Continue practicing the **INTENTIONAL DIALOGUE** (2-3 times a week).

Session 5
Sexual Enhancement and Problem Solving

This session will focus on problem solving and coping, whereby changes to women's sexual responsiveness and/or anatomy, as well as specific problems related to the couple's intimacy and sex life are addressed. Couples will also be provided with specific information about sexual strategies to enhance intimacy and sexual satisfaction.

Session Goals:

i) To explore, validate, and normalize couples' practical challenges to having sex.
ii) To encourage couples' mutual planning and initiation of sex.
iii) To facilitate acceptance, flexibility, and sexual problem solving.
iv) To provide solutions, strategies, and resources relevant to couples' challenges.
v) Use homework from session 4 (remembering a time you felt sexually connected to your partner) to help guide this dialogue.

Check in and Homework Review

Sensate Focusing
Did you practice any sensate focusing over the week? What was it like? What was your experience as giver/receiver? What was the experience of incorporating breast and erogenous zones. What did you notice? Challenges? Questions? Validate experiences. Address challenges.

Intentional Dialogue
Briefly check in with intentional dialogue. Encourage couples to continue with exercise. Did it make you feel closer?

Intimacy Wish list Application
How did the intimacy wish list exercise go? What was it like giving? What was it like receiving? What did you notice? Challenges? Questions? Validate experiences. Address challenges.

Exploring Sexual Challenges
Discussion Points. The goal is to identify, normalize, and validate, couples' practical challenges with having sex (e.g., scheduling, pain, discomfort)

i) What are some of things that have been difficult or do you think will make it challenging for you when it comes to sex (probe for pain, dryness, low libido, fatigue, planning, time).
ii) What do you find sexually pleasurable? What makes you feel good, gets you aroused?
iii) Is there anything you did before that you would like to do now but worry about?
iv) Is there anything you've always wanted to do or try and had been too shy to talk about or just never got around to?

Solutions and Strategies

i) Planning SEX

What is a day or time that you could schedule a "date night."

- Initiating sex also involves planning sex**,** this will involve scheduling sex – picking a day and a time, setting a "date night."
- This is often difficult for couples to accept. We generally want sex to be spontaneous; we don't want it to be something we "have to do." But for many people - people with kids, with busy jobs, scheduling is necessary part.
- Emphasize that scheduled sex can be great sex. *"A scheduled meal with a friend is still as tasty as a spontaneous one."*
- Create a sensual mood (lighting, music, scents, romantic meal) - back to basics.
- Again, wear something that makes you feel good (soft fabrics, negligee).
- Find other ways to feel good, to ease into it – a sensual massage (maybe with a nice massage oil), caressing other erogenous zones.

ii) Initiation of sex

How can we share the initiation of sex? What might that look like in the beginning?

- Share responsibility for initiation of sex.
- Communicate about expectations, be open and honest about expectations and assumptions.
- Be open to new experiences.
- Engage in sexual activity without waiting for sexual arousal.

iii) Once you are in the throws…

- Be open to new experiences!!
- Prolong foreplay (spend time touching and pleasuring each other to prime/prepare the body).
- Engage in non-penetrative sexual activity – touching, introducing toy play, oral sex.
- VIBRATORS are fantastic!
- For women who are experiencing genital numbness, or their brain is getting in the way, (i.e., bleeding, first attempt was painful) which leads to anxious anticipation, which can lead to problems achieving orgasm – vibrators are great.
- Assume a position during intercourse to allow control of rate and depth of penetration (e.g., female on top.) Explore couple's preferences and comfort levels and provide positions accordingly

iv) Vaginal Dryness and Vaginal Pain

Vaginal lubricants

- There are a lot of really great lubricants out there that are safe.
- Astroglyde is a lube that is glycerine, paraben, and alcohol free.
- It's a great lube, it's water soluble and won't stain the sheets.
- Other lubricants like Wet and Sylk are also great.
- KY Jelly is not the best selection for lubrication – sticky, stains sheets.

Moisturizers

- For women with daily dryness and discomfort (not just in the context of intercourse)
- This can include capsules that are inserted into your vagina and gradually release moisturizer. Women don't always like this, because it initially leads to discharge.
- Remember, ***Moisturizers = Maintenance, Lubrication = Love making***
- For vulvar dryness, use vitamin E capsules around vulva and entrance to the vagina. Vitamin E capsules are SAFE and SOOTHING

v) Shifting expectations

- Many couples experience pressure and expectation that they need to find their way back to the way sex was before the breast cancer. The idea of getting "back to normal." Women and couples need to embrace a "NEW NORMAL" and acknowledge that yes, things will be different but it doesn't mean they are not as good. In fact, it can actually be better, I've used the term "ALTERED SEXUALITY" a few times and I encourage you to hold on to the idea of "ALTERED SEXUALITY" rather than LOST or DAMAGED SEXUALITY.
- Again, as a first step it is important to acknowledge and mourn the loss of the way things were, mourn the loss of your breasts, of the way sex used to be.
- BUT be open to new experiences, embrace new experiences, use this as an opportunity to maybe try something you haven't tried or maybe have been curious to try but were previously to embarrassed.
- Remember that although it can feel that breast cancer has forced you to actively work at restoring/improving your sexual relationship, ***it can also be an opportunity for growth and exploration, and opens of the possibility of sex being even better than it was before.***

vi) Psychoeducation about arousal

EXPLAIN: Men typically feel spontaneous desire, which leads to arousal. BUT for women, sexual desire is often triggered by arousal (desire comes AFTER becoming aroused). For many the norm is for foreplay to elicit arousal, with that arousal resulting in feeling desire. Don't wait for spontaneous arousal to initiate sex.

Introduce Homework

1) Sensate Focusing

STAGE FOUR introduces penetration and/or intercourse. Continue to pay attention to the areas of the body from the previous stages. Again, start with other areas of the body, including the breasts and nipples. Continue on to the areas around the genitals, eventually touching the genitals. Continue with the teasing technique. Increase the speed and pressure if you and your partner are comfortable with this, and then take a break. Incorporate gentle forms of penetration; try this first with little or no thrusting, simply enjoying the sensation, and allowing your body to relax. The person being penetrated should be in control of the movements, speed, depth, and strength. Later you can incorporate more thrusting, but with the person being penetrated in control. Communication is key in this stage. While orgasm and intercourse are permitted, they aren't the goal. The goal is to feel connected and intimate. Many women have the expectation of pain when it comes to reintroducing penetrative sex (because it has been

painful in the past). This expectation can cause your body to tense up, making penetration uncomfortable and even painful. This is also why you might avoid having sex. This last stage is designed to help your body learn to relax and enjoy the sensations.

2) **Continue with Intimacy Wishlist exercise**

Wrap Up
Elicit and feedback questions.
Identify possible challenges and strategies for completing homework.

Session 5 Homework/Handout

1) SENSATE FOCUSING

Schedule 3 times during the week to practice **Stage Four** of the sensate focusing exercise. Each session can last 30-60 minutes. Start with one partner as receiver and then after 15-20 minutes, switch. See guidelines and helpful tips for sensate focusing below.

STAGE FOUR introduces penetration and/or intercourse. Continue to pay attention to the areas of the body from the previous stages. Again, start with other areas of the body, including the breasts and nipples. Continue on to the areas around the genitals, eventually touching the genitals. Continue with the teasing technique. Increase the speed and pressure if you and your partner are comfortable with this, and then take a break. Incorporate gentle forms of penetration; try this first with little or no thrusting, simply enjoying the sensation, and allowing your body to relax. The person being penetrated should be in control of the movements, speed, depth, and strength. Later you can incorporate more thrusting, but with the person being penetrated in control. Communication is key in this stage. While orgasm and intercourse are permitted, they aren't the goal. The goal is to feel connected and intimate. Many women have the expectation of pain when it comes to reintroducing penetrative sex (because it has been painful in the past). This expectation can cause your body to tense up, making penetration uncomfortable and even painful. This is also why you might avoid having sex. This last stage is designed to help your body learn to relax and enjoy the sensations.

2) Continue with **INTIMACY WISHLIST** exercise. Focus on the act of giving and expressing gratitude/appreciation.

Session 6
Consolidation and Moving Forward

Couples will consolidate what they have learned from the intervention and discus their goals and plans for resumption of a mutually satisfying sex life. The focus of this session is also to prepare and empower couples to move forward and continue working on their sexual relationship

Session Goals

i) Consolidate couple's experience of completing the program, including the degree to which the program has addressed their difficulties.
ii) Facilitate exploration of the sexual changes, and how these emerged.
iii) Identify elements that were most helpful and how.
iv) Identify goals for moving forward.
v) Identify potential challenges and barriers to moving forward, and discuss potential solutions and strategies.

Check in and Homework Review

Sensate Focusing
Did you practice any sensate focusing over the week? What was it like? What was your experience as giver/receiver? What was the experience of incorporating breast and erogenous zones. What did you notice? Challenges? Questions? Validate experiences. Address challenges.

Intimacy Wishlist
Briefly check in on the couples efforts to give and receive

Program Review and Moving Forward
Discussion Points:

1) Follow-up from last week. Questions, thoughts?

2) Review the program, summary of sessions, and the couple's experience and progress through the program.

3) Moving forward, what are some things you will take away with you? What are some anticipated challenges/barriers to these goals? Potential solutions.

4) To what extent have your difficulties with sexual intimacy been resolved since you began this program?
   i) Female
   ii) Partner

5) As specifically as possible, please describe the changes have you seen in yourself and in your partner with respect to your sexual relationship?

i) Female
ii) Partner

6) What do you think brought about the changes you've described?

7) What did you learn about yourselves, your sexual relationships?

8) What will you take away with you from this program?

Appendix H: Program Review Handout

Sex and Intimacy Program Overview

Communication Skill Building

- ***Tool/Strategy:*** Intentional Dialogue (refer to homework review)

Let's Talk about Sex!

- Exploring what you and your partner value about sex in the context of pleasure and connection. What makes you and your partner feel good physically? What makes you and your partner feel close and connected? These concepts can be applied both inside and outside of the bedroom.
- ***Tool/Strategy:*** Intimacy Wish List (refer to homework review)

Impact of Breast Cancer on your Sexual Relationship

Psychological and Emotional Impact

- Breast cancer can impact your sexual relationship at all stages of the illness, including the initial shock of diagnosis, going through treatment, sex falling by the wayside due to managing cancer and other responsibilities, changes in your body, changes in your mood (e.g., anxiety or depression), and how you relate to/interact with each other
- You've both been through a major stressor, and while this can bring a couple closer together, it can also feel like a strain on the relationship
- Each of you may have your own struggles - some may be the same, some may be different; you also share and experience challenges/struggles as a couple

Physiological/Anatomical Impact

- Breast cancer and its associated treatments can lead to changes in sexual responsiveness and/or anatomy that make sex challenging or less enjoyable (e.g., pain, low libido, dryness, fatigue, etc.)

Tools/Strategies:

- Finding ways to reconnect with your body and experience it as an area of pleasure (e.g., day at the spa/salon, manicure/pedicure, getting a massage, taking a relaxing bath, wearing makeup, clothes, and fabrics that make you feel good). What makes you feel good is a personal choice…remember this is not limited to feeling good in the bedroom
- What can you and your partner do to make each other feel good and/or attractive?
- ***Expressing Affection:*** finding ways to feel intimate and connected even when you aren't having sex. Remember that stopping sexual activity does not have to mean stopping other forms of physical affection. Even when you *are* sexually active, other

forms of physical affection can help to enhance the relationship and your feelings of closeness.

- Adjusting to changes in your sexual and intimate relationship: ***Shifting from*** "It will never be the same again" to "Life will be different, but we have the resources and we can find new ways of being satisfied with our intimacy."
- ***Planning/Scheduling*** sex and/or date nights
- ***Sharing initiation*** of sex or sexual activities
- Be open to and curious about new activities, prolong foreplay, engage in non-penetrative sexual activities

Moving Forward

Where do we go from here?

Great work and congratulations on having given yourselves the time and opportunity to take part in this program. You both made the decision to be proactive in improving your sexual and intimate relationship, and took the first step by meeting every week with your counselor. Remember that just because the program has ended does not mean that your forward momentum needs to stop. Below are a few tips and strategies for continuing to nurture your sexual relationship and incorporating what you've learned from the program into your lives.

Prioritizing Your Relationship

While scheduling may feel challenging, awkward, and forced at first, the short- and long-term benefits of scheduling time together are worth this extra effort. One way to address these challenges is to reframe the concept of scheduling into **PRIORITIZING** your relationship. ***Sex doesn't need to be spontaneous to be great!***

> ***Scheduling can include:*** sex (not limited to intercourse), sensate focusing, date nights, alone time, activities, a short walk, 15 minutes of dedicated time to simply enjoy each other's company at the end of the day or before bed, etc. Remember, there will always be something keeping you busy, and it may seem like there is no room/time for your relationship. This is why scheduling is so important! As with any new activity or habit, this may seem effortful at first, but with time you will find yourselves making room in your schedules with more ease.
>
> For six weeks, you and your partner committed to and arranged your schedules to participate in this program. As you and your partner move forward, I encourage you both to continue setting this timeslot aside as **your own personal "check in" time**. Keep yourselves accountable. This may include:
>
> - Reviewing the key points of the program in this handout, including the homework. Are there any topics you and your partner would like to revisit? Any tools or strategies you and your partner want to focus more closely on? What would you and your partner need or like to work on in order to maintain this forward momentum?
> - Discussing challenges or difficulties that may have come up during the week and incorporating tools or strategies you learned from the program.
> - Using this time to make a relationship schedule for the week: scheduling time together for sex, date nights, activities, alone time

Communication is Key!

In addition to having learned a new communication skill, this program also provided you and your partner with a platform to talk about your experiences, feelings, concerns, wants, needs, etc. While talking about these issues can sometimes feel uncomfortable or awkward, communication is essential to making a relationship work.

Think of communication as the bridge back to sex… we need that bridge to be solid so that we can cross it.

Be Curious and Creative

Think of this as an exciting time for you and your partner to try new things! This is not limited to sex...although this can certainly be a fun part of it. This can include findings new ways to connect and feel close…perhaps starting a new activity together, making an active effort to spend more time together, and/or establishing a regular 'date night' once a week or every other week. This is an opportunity for you and your partner to learn new things about yourselves and each other, and to rediscover who you want to be as a couple.

As you and your partner continue to rebuild your sexual and intimate relationship in this new post-cancer territory, remember: *Acceptance, Flexibility, and Persistence*

> ***Acceptance:*** Accepting what you are given. Assessing the situation and developing realistic expectations about your current and future sexual relationship. Fighting against this and trying (or waiting) to get back to the way things were can lead to frustration, and resentment, and is emotionally draining. When we can set this frustration aside, we are able to consider alternative ways and solutions to regaining and maintaining a sexual relationship. Acceptance also means acknowledging the grief and how you feel about the loss of your old sexual relationship (this can include loss of breasts, loss of certain sexual activities). It's ok to be sad and miss these things.
>
> ***Flexibility:*** This is the willingness and ability to adapt and be flexible. This means being flexible and modifying previous ways of having sex. This requires being open to and experimenting with new sexual/sensual activities and ways of being physical.
>
> ***Persistence:*** Ability to try again despite difficulties and barriers. Trying things a few times even when they feel new, awkward, or uncomfortable. Continuing to try new things. Don't' give up because something didn't work the first time.

Homework Review

Intentional Dialogue

Intentional dialogue is a communication skill that can help deepen your understanding of your partner and his/her experience and/or see things from a new and different perspective. One of the ways this exercise does this is by helping us slow down the natural flow of the communication process, so that we can better hear our partners. These skills can be used to enhance communication about all topics/issues, including sex and intimacy. Intentional dialogue can feel awkward at first, but with practice it can be a very useful tool. Remember, communication is essential when it comes to sex and intimacy.

Schedule time to practice intentional dialogue. This can be a spontaneous topic that comes up for you during the day/week or something that you've wanted to discuss with your partner. As the speaker, remember to speak from your experience, using "I" language. As the listener you will mirror, validate, and empathize, holding back any reactions you may have. This isn't always easy, but you can discuss or explore your reactions during a debrief, or through a separate intentional dialogue. Take your time, it will feel awkward to slow things down!

Mirroring: You will mirror your partner's statement back to them to confirm that you understand the sentiment being expressed. Basically, you can repeat what your partner is saying to you in your own words. This can start with things like "So what I'm hearing you say is that…" Asking your partner "Is that right? Is there more?" gives him/her the opportunity add anything you may have missed.
Validating: Offer validation, allowing your partner to hear that he/she is entitled to his/her feelings. "It makes sense to me that you would…" Don't just say that you understand. Tell your partner what it is that you understand.
Empathy: Making sure you understand how they are ***feeling***. What is the underlying message here? Are they feeling confused, frustrated, scared, lonely, rejected? Providing empathy not only helps you better understand what your partner is expressing, but also helps them feel heard and understood by you. This can help you grow closer and feel more connected. i.e., " from what I understand about you…you must be feeling very x, y, or z"

Sensate Focusing

Sensate focusing is a series of techniques that progress through four stages with the goal being not to achieve orgasm, but to ***have an appreciation of a whole new set of sensual possibilities.*** ***Intercourse and orgasm are not the ultimate goals here.*** Another goal of this exercise is to ***build trust and intimacy*** within your relationship, helping you and your partner to give and receive pleasure. It ***emphasizes positive emotions, sensations, and responses while reducing any negative reactions***. This exercise can help overcome any anxiety or fears that may have existed previously, building a more satisfying sexual relationship in which you and your partner feel free to ask for what you want and are able to give and receive pleasure. *Sensate focusing emphasizes being fully present in the moment and enjoying the experience of being physical with each other.*

Sensate focusing progresses through several stages. The exercises are done in steps over a period of time. Typically, ***each session lasts twenty to sixty minutes, two to three times a week, and is spread over six or more weeks.*** The pace depends on your progress and comfort. Sensate Focusing is not a race to an end. How long you spend doing this is up to you. ***Do not change stages until both of you are ready.***

General Guidelines

- Schedule a time that is suitable for the both of you.
- Turn off your phones, television, and eliminate all other sources of distraction.
- Set an environment that is soothing and comfortable; this could include things like soft music, candles, scents you and your partner find pleasant, massage oils, etc.
- You and your partner can be naked, wear underwear or other comfortable clothing – whatever you are most comfortable with.
- ***If you are the GIVER:*** Take time to explore your partner's body, taking pleasure in experiencing things like different textures and shapes. Try to discover the different types of touch and pressure that your partner finds most enjoyable. Comment on what you notice or enjoy about the activity and/or your partner's body.
- ***If you are the RECEIVER:*** Remember, arousal is not the goal here. Rather, focus on the different sensations as your partner explores your body and touches your skin. Be open and communicate what you like and don't like. Use encouraging language like "I like it better when…" and avoid saying things like "Don't…" as this can be discouraging.
- It is helpful to talk about your experiences as giver and receiver after each exercise. Talk about what you enjoyed as giver and receiver. Don't be afraid to talk about something you might like to try.
- During each stage, partners take turns being the giver and the receiver. After 15-30 minutes (or longer if you like) change roles.

STAGE ONE involves touching each other's bodies in areas that are NOT sexually stimulating, (no touching of genitals and breasts). Intercourse is also not allowed. ***The goal of this stage is to enjoy and become increasingly aware of qualities of your partner's body, including the shape of each section, and texture of their skin***. Focus on what you find interesting about your partner's body, not on what you think they may enjoy. Focus on the parts of the body that are normally visible, including face, head, scalp, arms, hands and feet. When you feel ready, include neck, back, buttocks, and legs. Finally, touch the chest, stomach, shoulders, and thighs (avoid the genitals and breasts). While arousal can be a pleasant and welcome part of this exercise, it is not the goal.

STAGE TWO continues with the type of touch and exploration in stage one, but increases touch options to include breasts and nipples (remember men have nipples too!). Continue to pay attention to the areas of the body from stage one while incorporating these new areas. In addition to breasts and nipples, explore other erogenous zones and areas of sensual pleasure like inner thighs and areas around and close to the genitals. ***The main goal of this stage is to increase each person's pleasure and awareness of each other's responses to different types of stimulation.*** In this stage, the "receiver" can also place their hand over the "giver's" hand in order to show what they find pleasurable in terms of pace and pressure. If one or both of you become aroused, this is fine but it is not the aim of the exercise.

In **STAGE THREE,** you can gradually include touching of the genitals. Start with breasts and nipples (if you are comfortable with this). Don't forget to pay attention to the other parts of the body from stages one and two. Continue on to the areas around the genitals, including the testicles. Then introduce the genitals themselves, including the clitoris and entrance to the vagina on the woman, and the penis and shaft on the man. You can introduce a teasing technique, which involves manually stimulating your partner for a while and then taking a break. Intercourse and penetration are not permitted in this stage. Experiment with different sensations, pressure, and speed. You may wish to include lubricants in this stage.

STAGE FOUR introduces penetration and/or intercourse. Continue to pay attention to the areas of the body from the previous stages. Again, start with other areas of the body, including the breasts and nipples. Continue on to the areas around the genitals, eventually touching the genitals. Continue with the teasing technique. Increase the speed and pressure if you and your partner are comfortable with this, and then take a break. Incorporate gentle forms of penetration; try this first with little or no thrusting, simply enjoying and being mindful of the sensation, and allowing your body to relax. The person being penetrated should be in control of the movements, speed, depth, and strength. Later you can incorporate more thrusting, but with the person being penetrated in control. Communication is key in this stage. While orgasm and intercourse are permitted, they aren't the goal. The goal is to feel connected and intimate. Many women have the expectation of pain when it comes to reintroducing penetrative sex (because it has been painful in the past). This expectation can cause your body to tense up, making penetration uncomfortable and even painful. This is also why you might avoid having sex. This last stage is designed to help your body learn to relax and enjoy the sensations.

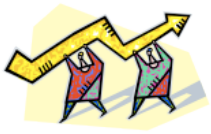
Intimacy Wishlist

1) Build upon, revise, or expand ***Intimacy Wish List:***

- Come up with a wish list of things both you and your partner could do to feel closer to and more connected to one another. Ask yourselves:
- What are some day-to-day things that your partner does for you (or that you do together) that make you feel closer and more connected? Those little things that make you smile ☺
- What are some things that you and your partner could do or schedule together that help to enhance this sense of closeness?
- What are some "bedroom related" things what would make you and your partner feel more connected. What are some things you might like to try or do differently that would feel physically pleasurable to you.
- ***Remember to be specific – focus on behaviors and things that are tangible.***

2) Select items from your partner's intimacy wish list that you would like to do for them. Remember, this is not a contest. It is about enjoying the act of giving and doing something for your partner and acknowledging/appreciating your partner's efforts of giving these things to you.

Additional Resources



Lubricants

- Lubricants are used during sexual activity, including intercourse
- Astroglyde is a lubricant that is glycerine, paraben, and alcohol free. It is also water soluble and won't stain the sheets.
- Other lubricants like Wet and Sylk are also great
- There are also natural lubricants

Moisturizers

- Moisturizers are used for daily dryness and discomfort
- This can include capsules that are inserted into your vagina that gradually release moisturizer. Women don't always like this, because it initially leads to discharge.
- For vulvar dryness, use vitamin E capsules around vulva and entrance to the vagina. Vitamin E capsules are SAFE and SOOTHING

- When shopping, remember ***Moisturizers = Maintenance, Lubrication = Love making***

Female-Centric Adult Stores

These shops sell a wide range of toys, lubricants, books, videos, etc. They also offer workshops.

Good for Her *http://www.goodforher.com/*
Come as You Are *http://www.comeasyouare.com/*

Websites and Additional Reading

Red Tent Sisters. *http://www.redtentsisters.com*
This website includes a variety of resources about sexuality, sexual health, and intimacy, including readings, blogs, programs, and information about natural sex toys, lubricants, and oils.

EcoSex *https://www.ecosex.ca/*
Created by the team behind Red Tent Sisters, this online store includes a variety of natural sex toys, lubricants, and oils.

The Seven Principles for Making Marriage Work: A Practical Guide from the Country's Foremost Relationship Expert by Dr. John Gottman and Nan Silver

Positive Couple Therapy by Jefferson Singer & Karen Skerrett

Both of these books are great for couples who would like to reclaim, reignite, and enhance their relationship.

Appendix I: Consent Form

Sunnybrook Health Sciences Centre
2075 Bayview Avenue,
Toronto, ON Canada M4N 3M5
t: 416.480.6100
www.sunnybrook.ca

INFORMED CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Full Study Title: An Evaluation of an Internet-based, Psychosexual Intervention for Couples following Treatment for Breast Cancer: A Phase I Trial

Principal Investigator: Karen Fergus, PhD, CPsych, Patient and Family Support, [redacted]

Co-Investigator: Kimberley Cullen, MA, PhD Candidate, York University

Sponsor: This study is being funded by Canadian Breast Cancer Foundation – Ontario Region

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INFORMED CONSENT

You are being asked to consider participating in a research study. A research study is a way of gathering information on a treatment, procedure or medical device or to answer a question about something that is not well understood.

This form explains the purpose of this research study, provides information about the study including the procedures involved, possible risks and benefits, and the rights of participants.

Please read this form carefully and ask any questions you may have. You may have this form and all information concerning the study explained to you. If you wish, someone may be available to verbally translate this form into your preferred language. You may take as much time as you wish to decide whether or not to participate. Feel free to discuss it with your friends and family, or your family doctor. Please ask the study staff or one of the investigator(s) to clarify anything you do not understand or would like to know more about. Make sure all your questions are answered to your satisfaction before deciding whether to participate in this research study.

Participating in this study is your choice (voluntary). You have the right to choose not to participate, or to stop participating in this study at any time.

INTRODUCTION

You are being asked to consider participating in this study because you are a woman who has been diagnosed with breast cancer, or you are her partner. As a result of diagnosis and treatment of breast cancer, couples often encounter sexual difficulties including decreased sexual desire and/or satisfaction. Unfortunately, programs for couples facing these issues are limited. This is a study about the helpfulness of an eTherapy program specifically tailored for couples experiencing concerns in relation to sexual intimacy following breast cancer. The purpose of this program is to provide couples with education, support, and tools for addressing these issues. This online program involves 6 weekly sessions of couples-based counselling delivered via videoconferencing. The time commitment for each individual participating in the program is approximately 1.5 hours every week for approximately 6 weeks.

WHY IS THIS STUDY BEING DONE?

The purpose of the study is to evaluate whether the online psychosexual intervention is useful, and to determine what aspects of the program participants benefited from the most, and areas in need of improvement.

WHAT WILL HAPPEN DURING THIS STUDY AND WHAT ARE YOUR RESPONSIBILITIES?

If you decide to participate in this study you will be asked to do the following:

(1) Completion of a questionnaire package before and after the online program, as well as three months following completion of the program. The questionnaire package will take approximately 45 minutes to complete.

As part of your participation, you will be asked to complete a questionnaire package. The questions will pertain to sexuality and intimacy (e.g., activities, satisfaction, difficulties), your relationship (e.g., shared activities, communication, demonstrations of affection), mood and well-being, and coping. Both you and your partner will be asked to answer the questionnaires independent of each other. You will not have access to your partner's answers and vice-versa. You will be asked to complete the questionnaire package on three occasions: (1) before you begin the study, (3) upon completion of the study (approximately six weeks later) and (4) three months after the 6 week time point. You will also be asked to complete a questionnaire pertaining to demographic and relevant health information prior to starting the program.

(2) You will be asked to complete six weekly psychosexual counselling sessions over the course of approximately 6 weeks. Each session will focus on areas relevant to sex therapy and sexual dysfunction in couples facing breast cancer (e.g., education, communication, body imagery, sensate focusing, and problem solving). Sessions will be approximately 1.5 hours in length, during which you and your partner will meet with a facilitator via videoconferencing in the comfort of your own home. Sessions will be audio recorded for supervisory purposes. Each session will be supplemented with psychoeducational materials (i.e., readings and/or video), which will be sent to you via email.

(3) You will also be asked to participate in pre- and post-treatment interviews. The purpose of the pre-treatment interview is to enable the facilitator to have a clearer understanding of the difficulties you have identified as problematic in your sexual relationship, as well as your expectations for the intervention. The pre-treatment interview will take place over the telephone or using video conferencing software, be audio recorded, and last for approximately 1 hour. The recordings will be transcribed and the transcripts will be analyzed to determine common themes across all participants. The purpose of the post-treatment interview is to provide a conclusion to your participation in the project, and to gain feedback from you about whether you found the program helpful and how it could be improved. The post-treatment interview will take place after completion of the intervention, be audio recorded, and last for approximately 1 hour. The recordings will be transcribed and the transcripts will be analyzed to determine common themes across all participants.

(4) You may be contacted at a future date to participate in a follow-up interview. The purpose of the interview will be to gain a more in-depth understanding of your experience with breast cancer, sexuality, intimacy, and participation in this project. The follow-up interview will be conducted by a member of Dr. Fergus' Psycho-Oncology Research Team, and will last for approximately 1 hour. The recordings will be transcribed and the transcripts will be analyzed to determine common themes across all participants.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

It is anticipated that about 25 couples (50 people) will participate in this study, and recruitment will be through the Sunnybrook Odette Centre and announcements in the Greater Toronto Area. The length of this study for participants is approximately 6 weeks for the intervention, with the completion of an additional questionnaire package three months following completion of the program. The entire study is expected to take about 3 years to complete and the results should be known in 3.5 years

WHAT ARE THE RISKS OR HARMS OF PARTICIPATING IN THIS STUDY?

The potential risks associated with participating in this study are minimal and strategies have been put in place to mitigate these risks. There are no medical risks to you from participating in this study. Given the personal nature of this study, taking part may make you feel uncomfortable or embarrassed at times. In the unlikely event that you experience an increase in relationship distress over the course of the program, you will have the option of referral to a couple therapist.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

You may or may not benefit directly from participating in this study. However, possible benefits include increased knowledge about the impact of breast cancer on sexuality and sexual fucntioning, enhanced sexual satisfaction and feelings of closeness and intimacy, along with improvements in communication. Your participation may or may not help other people with breast cancer in the future.

CAN PARTICIPATION IN THIS STUDY END EARLY?

You are free to discontinue participating in the above stated project at any time you choose with no effect on your health care. You may refuse to answer any questions, or terminate you involvement in the online intervention, or refuse to complete the questionnaires at any time. If you choose to withdraw from the study at any point, you may request to have the information accumulated up to that point, destroyed.

The investigators may decide to remove you from the study without your consent for at least one of the following reasons:

- The investigator(s) decides that continuing in this study would be harmful to you.
- You are unable or unwilling to follow the study procedures or requirements.

If you are removed from this study, the investigator will discuss the reasons with you and plans will be made for your continued care outside of the study.

WHAT ARE THE COSTS OF PARTICIPATING IN THIS STUDY?

Participation in this study will not involve any additional costs to you.

ARE STUDY PARTICIPANTS PAID TO PARTICIPATE IN THIS STUDY?

You will not be paid to participate in this study.

HOW WILL MY INFORMATION BE KEPT CONFIDENTIAL?

Every precaution will be taken to ensure that your privacy and confidentiality are maintained. eTherapy sessions will be conducted using secure, encrypted videoconferencing software that does not record or store data on its server, and is commonly used by health care providers practicing Telemedicine. Finally, you will be assigned couple and individual ID numbers, and you will be identified by these numbers on your questionnaire responses.

Electronic records including audio digital recordings of the session, interview transcripts, data, and any other electronic documents containing personal information will be password protected on a secure server, on encrypted USB drives, and/or on laptops with encrypted hard drives. Hardcopy documents including consent forms, list of ID numbers and participant names, and any other documents with personal information will be stored in a locked cabinet in a locked office space. Hard copies of questionnaires and interview transcripts will be stored in a separate locked cabinet in a locked office space.

You will not be identified by name on any document. Your identity will remain confidential. The findings will be published in academic journals and presented to professional and general audiences. It is possible that word-for-word excerpts from your interviews and comments may be used in presentations and reports. Were this to occur, your identity would be concealed and protected. However, it is possible that you (or people who know you well) might recognize words-in-print or spoken in a presentation as belonging to you.

DO THE INVESTIGATORS HAVE ANY CONFLICTS OF INTEREST?

There are no conflicts of interest to declare related to this study.

WHAT ARE THE RIGHTS OF PARTICIPANTS IN A RESEARCH STUDY?

You have the right to receive all information that could help you make a decision about participating in this study. You also have the right to ask questions about this study and your rights as a research participant, and to have them answered to your satisfaction, before you make any decision. You also have the right to ask questions and to receive answers throughout this study.

If you have any questions about this study you may contact the person in charge of this study (Principal Investigator) Karen Fergus, PhD, C.Psych, Odette Cancer Centre, [redacted]

The Sunnybrook Research Ethics Board has reviewed this study. If you have questions about your rights as a research participant or any ethical issues related to this study that you wish to discuss with someone not directly involved with the study, you may call **Dr. Philip C. Hébert, Chair of the Sunnybrook Research Ethics Board at (**[redacted]

This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact the Sr. Manager & Policy Advisor for the Office of Research Ethics, 5th Floor, York Research Tower, York University (telephone)[redacted] or e-mail)[redacted]

DOCUMENTATION OF INFORMED CONSENT

You will be given a copy of this informed consent form after it has been signed and dated by you and the study staff.

Full Study Title: An Evaluation of an Internet-based, Psychosexual Intervention for Couples following Treatment for Breast Cancer: A Phase I Trial

Name of Participant: _____

Participant/Substitute decision-maker

By signing this form, I confirm that:

- This research study has been fully explained to me and all of my questions answered to my satisfaction
- I understand the requirements of participating in this research study
- I have been informed of the risks and benefits, if any, of participating in this research study
- I have been informed of any alternatives to participating in this research study
- I have been informed of the rights of research participants
- I have read each page of this form
- I have agreed, or agree to allow the person I am responsible for, to participate in this research study
- This informed consent document may be placed in my medical records

_____	_____	_____
Name of participant/Substitute decision-maker (print)	Signature	Date

Person obtaining consent

By signing this form, I confirm that:

- This study and its purpose has been explained to the participant named above
- All questions asked by the participant have been answered
- I will give a copy of this signed and dated document to the participant

_____	_____	_____
Name of Person obtaining consent (print)	Signature	Date

Statement of Investigator

I acknowledge my responsibility for the care and well being of the above participant, to respect the rights and wishes of the participant as described in this informed consent document, and to conduct this study according to all applicable laws, regulations and guidelines relating to the ethical and legal conduct of research.

_____	_____	_____
Name of Investigator (print)	Signature	Date

Appendix J: Recruitment Materials

Sex after Breast Cancer: eTherapy for enhancing sex and intimacy in couples facing breast cancer

Did you know?

As a result of breast cancer and treatment side effects, couples often face challenges in their relationship, including those related to intimacy and sex. This program provides couples with tools and strategies to address these problems.

An Evaluation of an Internet-based Psychosexual Intervention for Couples following Treatment for Breast Cancer: A Phase I Trial

What is this research about?

The purpose of this research is to determine whether this program helps reduce sexual problems and enhance intimate relationships.

From the comfort of your own home, you and your partner will participate in 6 private sessions of couples counseling delivered via videoconferencing. Some topics will include communication, body image, and strategies for enhancing intimacy and/or sexual satisfaction. You will also receive educational materials to help guide you through the program.

In Support of Canadian Breast Cancer Foundation ONTARIO

YORK UNIVERSITÉ UNIVERSITY

Sunnybrook HEALTH SCIENCES CENTRE

Who is eligible to participate?

- **Women within 6 years of a breast cancer diagnosis**
- **Women who are at least 1 month post active treatment (e.g. surgery, chemo, radiation)**
- **Women who are in a committed relationship with a male partner**

What will participation involve?

Couples from across Ontario will participate in a 6-week counseling program. Participants will be asked to complete questionnaires before and after the program, and then again in three months. Couples will also participate in pre- and post-treatment interviews.

Interested in participating?

Principal investigator is Dr. Karen Fergus, Sunnybrook Odette Cancer Centre. To learn more about this program please contact the study coordinator:

[redacted]

Sex after Breast Cancer: eTherapy for enhancing sex and intimacy in couples facing breast cancer

Did you know?

As a result of breast cancer and treatment side effects, couples often face challenges in their relationship, including those related to intimacy and sex. This program provides couples with tools and strategies to address these problems.

An Evaluation of an Internet-based Psychosexual Intervention for Couples following Treatment for Breast Cancer: A Phase I Trial

What is this research about?

The purpose of this research is to determine whether this program helps reduce sexual problems and enhance intimate relationships.

From the comfort of your own home, you and your partner will participate in 6 private sessions of couples counseling delivered via videoconferencing. Some topics will include communication, body image, and strategies for enhancing intimacy and/or sexual satisfaction. You will also receive educational materials to help guide you through the program.

Who is eligible to participate?

- **Women within 6 years of a non-metastatic breast cancer diagnosis**
- **Women who are at least 1 month post active treatment (e.g. surgery, chemo, radiation)**
- **Women who are in a committed relationship with a male partner**

What will participation involve?

Couples from across Ontario will participate in a 6-week counseling program. Participants will be asked to complete questionnaires before and after the program, and then again in three months. Couples will also participate in pre- and post-treatment interviews.

Interested in participating?

Principal investigator is Dr. Karen Fergus, Sunnybrook Odette Cancer Centre. To learn more about this program please contact the study coordinator:

[redacted]

Note: Communication via email is not entirely secure, and those interested in participating are advised not to provide personal or sensitive information when contacting the study coordinator.

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UNIVERSITY

Appendix K: REB Approvals from York University HPRC, Sunnybrook Health Sciences Centre, and UHN

Certificate #:	**2013 - 230**
Approval Period:	**08/20/13-08/20/14**

Memo

OFFICE OF RESEARCH ETHICS (ORE)

5th Floor, Kaneff Tower

4700 Keele St.
Toronto ON
Canada M3J 1P3
Tel 416 736 5914
Fax 416 650-8197
www.research.yorku.ca

To: Professor Karen Fergus, Faculty of Health, [redacted]

From: Alison M. Collins-Mrakas, Sr. Manager and Policy Advisor, Research Ethics
(on behalf of Duff Waring, Chair, Human Participants Review Committee)

Date: **Tuesday, August 20, 2013**

Re: Ethics Approval

An Evaluation of an Internet-based, Psysosexual Intevention for Couples following Treatment for Breast Cancer: A Phase I Trial

I am writing to inform you that the Human Participants Review Sub-Committee has reviewed and approved the above project.

Should you have any questions, please feel free to contact me at: [redacted] or via email at: [redacted]

Yours sincerely,

Alison M. Collins-Mrakas M.Sc., LLM
Sr. Manager and Policy Advisor,
Office of Research Ethics

RESEARCH ETHICS: PROCEDURES to ENSURE ONGOING COMPLIANCE

Upon receipt of an ethics approval certificate, researchers are reminded that they are required to ensure that the following measures are undertaken so as to ensure on-going compliance with Senate and TCPS ethics guidelines:

1. **RENEWALS:** Research Ethics Approval certificates are subject to annual renewal.
    a. Researchers will be reminded by ORE, in advance of certificate expiry, that the certificate must be renewed
        i. Researchers have 2 weeks to comply to a reminder notice;
        ii. If researchers do not respond within 2 weeks, a final reminder will be forwarded. Researchers have one week to respond to the final notice;
    b. **Failure to renew an ethics approval certificate or** (to notify that no further research involving human participants will be undertaken) **may result in suspension of research cost fund and access to research funds may be suspended/withheld** ;

2. **AMENDMENTS:** Amendments must be reviewed and approved **PRIOR** to undertaking/making the proposed amendments to an approved ethics protocol;

3. **END OF PROJECT**: ORE must be notified when a project is complete;

4. **ADVERSE EVENTS**: Adverse events must be reported to ORE as soon as possible;

5. **AUDIT:**
    a. More than minimal risk research may be subject to an audit as per TCPS guidelines;
    b. A spot sample of minimal risk research may be subject to an audit as per TCPS guidelines.

FORMS: As per the above, the following forms relating to on-going research ethics compliance are available on the Research website:

a. Renewal
b. Amendment
c. End of Project
d. Adverse Event

Sunnybrook
HEALTH SCIENCES CENTRE

Research Ethics Office, Room C819
2075 Bayview Avenue
Toronto, ON Canada M4N 3M5
[redacted]
www.sunnybrook.ca/reo

To: Dr. Karen Fergus
Patient and Family Support
[redacted]

From: Dr. Philip Hébert

Date: August 2, 2013

Subject: **An Evaluation of an Internet-based, Psychosexual Intervention for Couples following Treatment for Breast Cancer: A Phase I Trial**

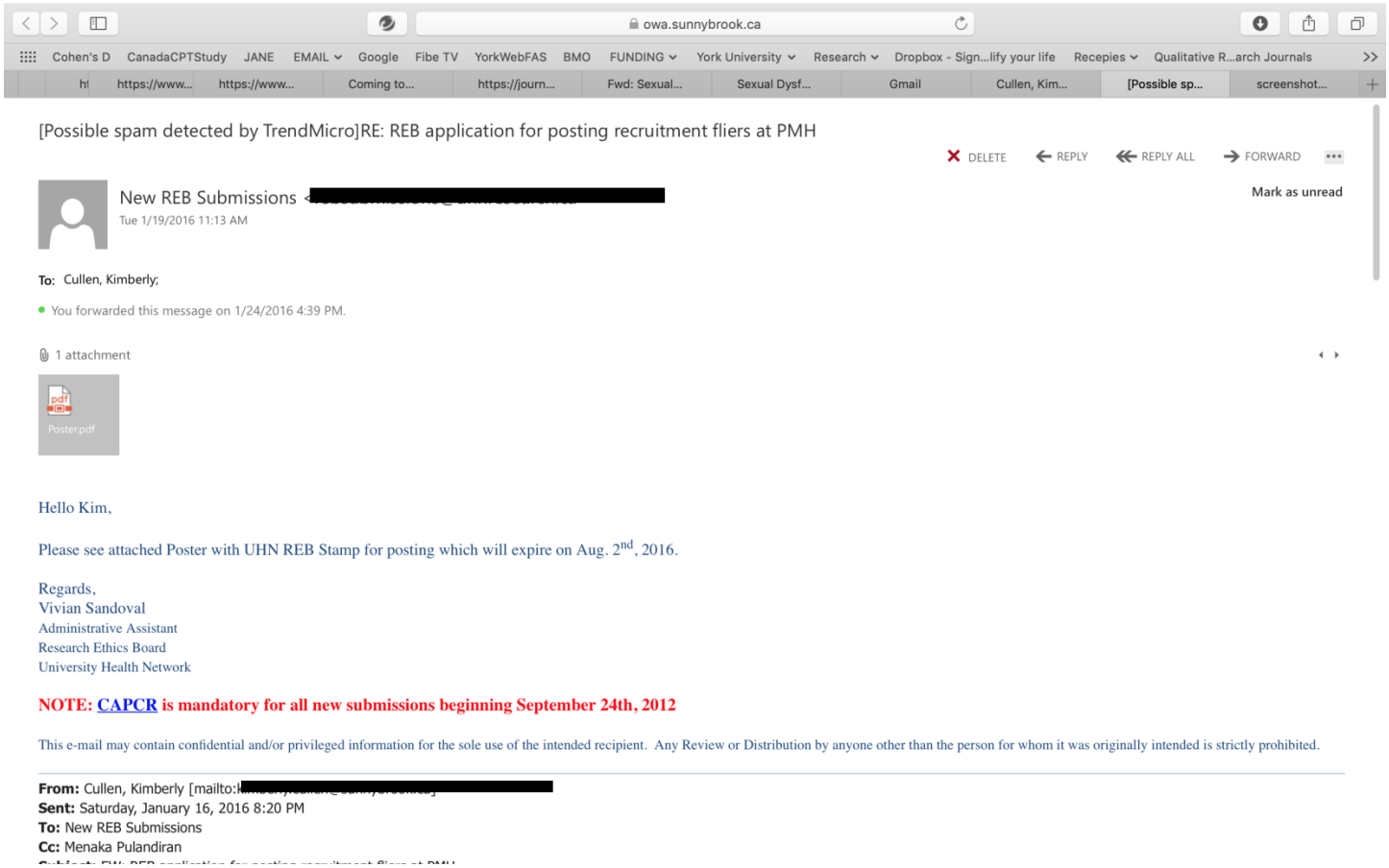
Project Identification Number: 227-2013
Approval Date: August 2, 2013
Expiry Date: August 2, 2014

The Research Ethics Board of Sunnybrook Health Sciences Centre has conducted a Delegated Board review of the research protocol referenced above and approved the involvement of human subjects on the above captioned date. The quorum for approval did not involve any member associated with this project.

The approval of this study includes the following documents:

- Protocol dated June 13, 2013
- Informed Consent Form Version 1 dated July 17, 2013
- Screening Questionnaire dated June 13, 2013
- Demographic Questionnaire dated June 13, 2013
- Program Expectancy Questionnaire dated June 13, 2013
- Sexual Function Questionnaire for Men and Women dated June 13, 2013
- Revised Dyadic Adjustment Scale dated June 13, 2013
- Dyadic Cohesion Subscale dated June 13, 2013
- Dyadic Adjustment Score dated June 13, 2013
- The Maudsley Marital Questionnaire – marital quality subscale dated June 13, 2013
- The Profile of Mood States-Short Form dated June 13, 2013
- FACT-B (Women) dated June 13, 2013
- Pre-treatment Clinical Interview dated June 13, 2013
- Post-treatment Clinical Interview dated June 13, 2013
- Poster (received June 17, 2013) **(Submit to Communications & Stakeholder Relations for approval prior to posting.)**

All correspondence with the REB must include the assigned Project Identification Number. The REB requires immediate notification of all internal serious adverse events and significant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[Possible spam detected by TrendMicro]RE: REB application for posting recruitment fliers at PMH
DELETE
REPLY
REPLY ALL
FORWARD
Mark as unread
New REB Submissions
Tue 1/19/2016 11:13 AM
To: Cullen, Kimberly;
You forwarded this message on 1/24/2016 4:39 PM.
1 attachment
Poster.pdf
Hello Kim,
Please see attached Poster with UHN REB Stamp for posting which will expire on Aug. 2nd, 2016.
Regards,
Vivian Sandoval
Administrative Assistant
Research Ethics Board
University Health Network
NOTE: CAPCR is mandatory for all new submissions beginning September 24th, 2012
This e-mail may contain confidential and/or privileged information for the sole use of the intended recipient. Any Review or Distribution by anyone other than the person for whom it was originally intended is strictly prohibited.
From: Cullen, Kimberly [mailto:
Sent: Saturday, January 16, 2016 8:20 PM
To: New REB Submissions
Cc: Menaka Pulandiran