

WOMEN'S EXPERIENCES COMPLETING AN ONLINE PSYCHOEDUCATIONAL
INTERVENTION FOR SEXUAL HEALTH AFTER CANCER: A NARRATIVE INQUIRY

by

Erin Nicole Breckon

B.A. (Honours in Psychology), University of British Columbia, 2009

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Abstract

Psychoeducational interventions have been found to be effective in helping patients with distressing sexual sequelae commonly experienced after cancer treatment that can persist for years. Geographical barriers, time, financial constraints, and embarrassment/ discomfort prevent a large number of patients from accessing in-person psychosexual support. Quantitative results of a pilot online psychoeducation intervention for sexual health after cancer (OPES) revealed the program helped improve sexually-related distress, depressive symptoms and all domains of sexual response (i.e., desire, arousal, orgasm, lubrication, satisfaction, and pain) among 46 partnered women which were maintained at the 6-month follow-up. A high attrition rate (56.25%) and lengthy program completion times (M=30 weeks) suggest the program may have been helpful for a subset of female reproductive and colorectal cancer survivors. The current study implemented a narrative methodology in order to gain deeper insight into how OPES was experienced by six women who completed the program. In in-depth, in-person, largely unstructured interviews were audio-recorded, transcribed verbatim, analysed, and constructed into 6 individual narrative summaries (presented in full). A cross-case analysis between the 6 summaries revealed several common themes and subthemes subsumed under perceived *benefits* and *challenges* in completing the program, *motivations*, and suggested *program improvements*. Results are presented herein. Individual bio-psycho-social factors influenced the degree of distress that women experienced in completing the program and how helpful it was in improving their “sexual functioning.” These findings highlight the importance of incorporating qualitative research in improving our understanding of how such programs are perceived and experienced as helpful by those who participate in them. Implications for future research on psychoeducational interventions for the sexual sequelae of cancer and its treatment are also discussed.

Preface

This thesis is an original, unpublished, independent work of the author, Erin Nicole Breckon.

This research was approved by the University of British Columbia's Behavioural Research Ethics Board as a qualitative follow-up study to a quantitative research protocol for a preliminary investigation of the Online Psychoeducation Intervention for Sexual Health in Cancer Survivors (OPES) conducted by Dr. Lori Brotto and colleagues. The UBC Ethics Certificate Number obtained to conduct the present research was H10-01032-A009.

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Dedication

In loving memory of my dad, Dr. Sidney Lawrence Breckon, whose care for and devotion to his patients as well as the provision of quality patient-centered health care has always been a source of inspiration to me. He was a much loved and respected doctor who will be sorely missed. His “get it done” attitude and words of support in our unbeknownst final conversation helped carry me along the final legs of this journey.

Chapter 1: Introduction

The purpose of the present study was to explore the lived experiences of women who completed a 12-week, online psychoeducation program aimed at healing the sexual aftermath of a cancer diagnosis and treatment for reproductive or colorectal cancers. My goal was to gain a deeper and more comprehensive understanding of female participants' motivations to participate in and complete the Online Psychoeducation for Sexual Health in Cancer Survivors (OPES) program, as well as their lived experiences of working through the program. I hope to learn about their successes, challenges and barriers in their efforts to improve their sexual lives and relationships after cancer treatment. These findings will help to improve the effectiveness of the OPES program. As well, the findings may provide health care professionals with important information about the needs and experiences of survivors of reproductive or colorectal cancers, so we may better support women in healing from the sexual aftermath of a cancer diagnosis and treatment.

Statement of the Problem

Since people diagnosed with cancer are now living longer lives after cancer diagnosis and treatment than ever before, maintaining or restoring "survivor" quality of life (QoL) has become an integral component of ongoing patient health care, oncology research, and clinical attention (Abbott-Anderson & Kwekkeboom, 2012; Bober & Varela, 2012). Sexual health has been recognized as an essential aspect of quality of life during and after cancer (Tierney, 2008). It has been well-established in the literature that cancer and its treatment can negatively and profoundly impact the cancer survivor's sexual wellbeing, across many cancer types, varying in the range of sexual difficulties experienced and levels of severity (Brotto, Yule, Breckon, 2010; Galbraith & Crighton, 2008; Hordern, 2008; Hughes 2008; Sadovsky et al., 2010; Varela, Zhou & Bober,

2013). Rates of various sexual complaints following cancer treatment have been estimated to be anywhere between 40% and 100% (Flynn et al., 2011) and can persist long after cancer has been cured and survivors resume their regular life activities (Burns, Costello, Ryan-Woolley, & Davidson, 2007; Krouse et al., 2007; Lindau, Gavrilova, & Anderson, 2007; Milbury, Cohen, Jenkins, Skibber, & Schover, 2013; Mirabeau-Beale & Viswanathan, 2014; Sadowsky et al., 2010). It is not uncommon for the experiencing of a cancer diagnosis to dramatically alter the way individuals feel about themselves, their bodies, and their significant relationships at sexual and intimate levels (Hawkins et al., 2009; Hordern, 2008). Furthermore, cancer and its treatment can exacerbate pre-existing sexual problems (Brotto, Yule, & Breckon, 2010). Sexual problems are especially relevant for survivors of reproductive and colorectal cancers as these cancers and their treatment involve those areas of the body (i.e., the breasts, vagina, vulva, clitoris, uterus, ovaries, cervix among women with breast and gynaecological cancers, and the internal and external genitalia and pelvic floor among people with colorectal cancer) that are mostly intimately associated with sexual pleasure and sexual functioning – and most representative of “sexuality” (Cleary & Hegarty, 2011; Hawkins et al., 2009; Hordern, 2008; Milbury et al., 2013; Wilmoth, 2001).

Although the definitions of sexual “dysfunctions” have been widely debated and have recently been revised in the updated Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013), sexual “dysfunction,” problems, or difficulties have largely been characterized in the literature as impacting any or all of the following sexual domains: desire (i.e., how interested one is in having sexual activity), arousal (i.e. penile erection for men and vaginal lubrication and sensitivity for women), orgasm, genital pain, and vaginismus (inability to permit vaginal penetration due to pelvic floor hypertonus)

(Brotto, Yule & Breckon, 2010; Tierney, 2008). Another important aspect of sexual health is an individual's subjective sense of sexual satisfaction (Traa, De Vries, Roukema, & Den Oudsten, 2012). Cancer treatments can have a direct, physiological impact on sexual response or an indirect effect on sexual wellbeing by affecting an individual's ability, motivation, or desire to participate in sexual activity. Cancer treatments can severely impact the integrity of the body resulting in such outcomes as scarring, chemotherapy induced alopecia, loss of body parts (i.e., mastectomy), weight gain, bladder and bowel dysfunction, and creation of a stoma for a colostomy or ileostomy. These outcomes can significantly impact women's body image and self-esteem in such a way that has further deleterious effects on sexual functioning and the desire to be sexual in a body that to some survivors, is no longer perceived as sexual or sexually attractive (Burns et al., 2007; Gilbert, Ussher, & Perz, 2011; Stead, Brown, Fallowfield, & Selby, 2003; Black, 2004).

It is very common among women diagnosed with, and treated for reproductive cancers (i.e., breast, ovarian, endometrial, cervical, and uterine) to experience a range of physical, psychological and social difficulties given that these cancers involve intimate areas related to, and representative of, women's sexuality, reproduction, and perceived femininity. An extensive body of research on gynaecological cancer survivors (see Abbott-Anderson & Kwekkeboom, 2012) has shown that physical sexual concerns, due to structural changes and changes in hormonal status, are commonplace including dyspareunia (painful intercourse), decreased vaginal elasticity and elongation, problems becoming aroused (i.e. vaginal dryness), vaginal stenosis (narrowing or loss of flexibility of the vagina), and ability to orgasm or quality of orgasm. Among psychological concerns, decreased sexual interest, diminished body image, changes in perceptions of femininity/ womanhood, and having fears and worries about resuming

sexual activity and experiencing real or perceived pain have also been reported in the literature (Abbott-Anderson & Kwekkeboom; Sadovsky et al., 2010). Furthermore, emotional variables such as strong feelings of grief, anxiety and depression, and a negative sexual self-schema can further impede a woman's sexual functioning or desire for sexual intimacy (Andersen, Woods, & Copeland, 1997; Sadovsky et al.; Tierney, 2008). Social sexual concerns that have been reported among gynaecological cancer survivors include difficulties communicating with their partner, perceived decrease in partner's interest in sexual activity, and concern over partner's perceptions (Abbott-Anderson & Kwekkeboom; Wimberly, Carver, Laurenceau, Harris, & Antoni, 2005). Although treatment for breast cancer does not involve the genitals, many similar difficulties have been reported in research on breast cancer survivors, such as changes in levels of sexual desire, diminished arousal, vaginal dryness and stenosis, orgasmic difficulties, pain, lowered self-esteem, poor body image, and problems with intimacy and in their relationships with their partner (Varela, Zhou, & Bober, 2013). These changes can reduce a woman's quality of life, emotionally (increasing anxiety and depression), relationally, and in terms of her sense of sexual attractiveness, femininity, and sense of herself as a sexual being (Ussher, Perz, & Gilbert, 2013a).

Treatments of colorectal cancers are known to negatively impact urinary function, fecal continence, and the sexual wellbeing and quality of life in both men and women (Breukink & Donavan, 2013; Milbury et al. 2013). Damage to various nerves, blood vessels, and surrounding tissues/ anatomy (which can include the ovaries or testes) from surgical procedures, radiotherapy, or chemotherapy, can cause erectile and ejaculatory problems among men, and problems with arousal (i.e., vaginal lubrication and swelling) and genital pain, and reduction in orgasmic capacity among women (Breukink & Donavan; Traa et al., 2012). Decreased levels of

sexual activity, reduced sexual satisfaction, enjoyment, and desire are also common, as well as negative body image (Donovan, Thompson, & Hoffs, 2010). Sexual problems have also been found to be more common among patients with an intestinal stoma (or ostomy) than those without (Reese et al., 2014; Ayaz & Kubilay, 2009). The negative impact of such sexual problems due to colorectal cancer treatments have been found to impact individuals' quality of life with respect to social functioning, financial difficulties, body image, self-esteem, as well as worry and distress (Black, 2004; Di Fabio, Koller, Nascimbeni, Talarico, & Salerni, 2008; Hendren et al., 2005)

Despite the high prevalence of sexual difficulties after cancer treatment, aside from pharmaceutical treatments for men such as Viagra and Cialis, the availability of evidence-based treatments or therapeutic support have been limited, although there has been an substantial increase in pilot studies of psychosocial or psychoeducational interventions in the past 5 years (Bober & Varela, 2012). A review of psychological intervention outcomes trials for sexual difficulties following cancer (Brotto, Yule, & Breckon, 2010) provides some supportive evidence for the feasibility and viability of psychological interventions for cancer survivors. However, it is unknown how readily available these interventions and programs are for the majority of cancer survivors (i.e., for those who are not interested in participating in efficacy research of interventions) or why they may not be considered an option by many cancer survivors with sexual complaints. More research is needed to illuminate what cancer survivors need, the accessibility of treatment options such as psychoeducational interventions, why patients are reluctant to access available interventions, and what they find most helpful in healing the sexual aftermath of cancer treatment. This study will focus on the latter – what survivors found helpful in assisting them with improving their sexual wellbeing.

Barriers to accessing psychosexual support for cancer survivors. Evidently, despite the prevalence of sexual problems among cancer survivors, addressing sexual quality of life has yet to be fully integrated into oncology care even for cancers involving the sexual organs (Flynn et al., 2012). Specialized sexual medicine (or sexual therapy clinics) is rare within larger cancer centers (Brotto, Yule, & Breckon 2010). Despite cancer survivors' strong desire to receive information and learn how to manage the impact treatment will have on their body, their intimate relationships, and their sexual wellbeing (Davison et al., 2002; Hordern & Street, 2007), many health care professionals do not routinely address these important issues with their patients (Stead et al., 2003; Ussher et al., 2013a; Ussher et al., 2013b). Survivors receive inadequate sexual health information during and after cancer treatment and many of their questions remained unanswered post-treatment (Bober & Varela, 2012).

Physicians receive inadequate training, if any at all, on addressing patient sexual concerns and oncologists have been found to be uncomfortable discussing sexual problems with their patients (Bober & Varela, 2012; Hordern & Street, 2007b). The following have been reported as barriers that physicians face in talking about sexuality and intimacy in the context of cancer with their patients: lack of time, lack of knowledge and education, personal attitudes/ biases and professional beliefs on appropriateness including embarrassment, and the use of distancing tactics (i.e., being vague or ambiguous) (Hordern, 2008; Ussher et al., 2013b). Unfortunately, there is sparse literature offering guidance or strategies for health care professionals on supporting their patients struggling with intimacy and sexual concerns during and after cancer treatment (Hordern, 2008). Bober and Varela (2012) point out that the absence of any discussion of sexuality in oncology care is problematic as it portrays an implicit (and unfortunate) message

that sexual problems are the natural consequence of treatment-related collateral damage that must be endured, which is certainly not the case.

Another significant issue to receiving adequate support and care of patient sexual concerns relates to geographic barriers (i.e., Ball et al., 2013). Many cancer survivors live in rural areas, at quite a distance from cancer centers or professionals providing sexual health services which are usually located in major cities. Time and cost may prevent those patients in rural areas from seeking out care. This can result in a large population of cancer survivors experiencing chronic sexual problems, with known negative effects on mood, quality of life and relationship status, without access to supportive care. Ball et al. (2013) report that embarrassment can act as another barrier preventing people seeking help with their sexual problems.

In order to address certain geographic and psychosocial barriers for cancer patients, internet-based psychological interventions are beginning to be investigated for their feasibility and effectiveness in helping men and women suffering from a wide range of chronic mental health issues, life crises, or illnesses (i.e. Murray, Burns, See Tai, Lai, & Nazareth, 2005; Tercyak, Mays, DeMarco, Sharff, & Friedman, 2012). There is emerging evidence suggesting online psychosocial and support groups are feasible and effective in helping increase patient access to cancer-related information and social support among cancer survivors as well as improving quality of life, mood, stress levels, and feelings of body image and sexuality (Classen et al., 2013; David, Schlenker, Prudlo, & Larbig, 2013; Schover et al., 2013; Stephen et al., 2013; Wiljer et al., 2011; Winzelberg et al., 2003).

OPES Program

In light of the geographical and psychosocial barriers to accessing support and treatment to heal the sexual sequelae of colorectal and gynaecological cancer, the Online Psychoeducation

for Sexual Health in Cancer Survivors (OPES) was created. A pilot study was carried out between 2010 and 2013 to assess the effectiveness of this online psychoeducational intervention aimed at healing the sexual aftermath, following the diagnosis and treatment of colorectal or gynaecological cancer (Brotto et al., 2015). The 12-module OPES program is an adaptation of a previously developed face-to-face psychoeducational intervention found to be effective in helping improve sexual functioning and distress, mood, and quality of life for women experiencing sexual difficulties following gynaecological cancer (Brotto et al., 2008; Brotto et al., 2012). OPES was adapted so that the program could be aimed at both women and men, and be appropriate for use with gynaecological and colorectal cancer patients. Being administered online, the program was geographically accessible to survivors throughout British Columbia (e.g., survivors living in more rural areas), and later in Windsor, Ontario and New York, NY and provided guidance and assistance for those who were experiencing barriers to communicating with their care providers about their sexual concerns.

The goals of the OPES program were to: 1) test an online psychoeducational intervention for women and men with sexual difficulties following treatment for colorectal, or for women who had gynaecological cancer; 2) improve participants' self-reported levels of sexually-related distress (primary outcome), and secondly, sexual functioning (in the domains of desire, satisfaction, sexual arousal/erection, orgasm, and sexual pain), depressive symptoms, relationship satisfaction, and quality of life, and 3) to assess gender differences in outcome measurements. OPES was aimed specifically for survivors of gynaecological and colorectal cancers rather than other cancers because sexual difficulties following surgical treatment for gynaecological and colorectal cancers have been well documented in the literature (i.e.

Sadovsky, et al.), and survivors of these cancers have been minimally studied with regards to treatment and support for their sexual complaints and concerns.

In my capacity as a research assistant (RA), I was responsible for: providing information about the program to those who were responding to letter invitations or advertisements, completing phone screening interviews to assess participant eligibility, sending and collecting informed consents, providing personalized passwords to participants to access to the password-protected website housing the confidential psychological assessment measures and the OPES treatment program materials, managing the online discussion board, supporting participants as they progressed through the modules, answering any questions or concerns, and tracking participant progress. I sent participants emails at the appropriate times, inviting them to complete their online questionnaires. When participants appeared to have stalled in their progress through a module, I sent email prompts to the participant after 2 to 3 weeks of no activity, checking in to see if s/he was experiencing any barriers (technical or otherwise) in completing that particular module. Through supporting participants as they worked through the 12 modules of the program and module exercises, I had the opportunity to build rapport with many participants. I was also able to learn about many of the challenges participants experienced in working through the OPES material and homework exercises (e.g., technical difficulties, busy schedules, illnesses, responsibilities caring for ailing parents, difficulties communicating with partners, etc.).

The quantitative analysis of the OPES program (to be discussed in chapter two) provided findings that raised additional questions about the content, format, and success of the OPES program. For example, the program experienced difficulties with recruitment, a high rate of attrition (57.5%), low male participation rates, and extensive time to program completion (average of approximately 30 weeks). Also women were more likely to complete all modules

and assessments than men (48.6% versus 32.5%) and showed greater improvements in mood, distress and sexual end-points than the men who completed the program. If programs like OPES are to be successful, it is important to learn more about the specific challenges, as well as benefits, experienced by participants who completed the program and what some of the motivating factors were in helping them complete the program. It is also important to gain some understanding of why it took participants significantly longer to complete the program than anticipated and expected.

Purpose of this Study

As a research assistant, through corresponding with, and supporting participants as they worked through the 12 modules of the OPES program, it became evident to me that people were experiencing a variety of challenges in progressing through the OPES psychoeducational material and homework exercises. However, many participants, especially women, reported a strong desire to continue working through the program and felt that participating in the program was beneficial, whether or not they completed the full 12 modules. Many questions remain unanswered after quantitative analyses were complete. How did participants navigate through their challenges to eventually complete the program? What parts were perceived as more and less beneficial? To what extent were participants able to incorporate the OPES program information and exercises into their intimate relationships? What motivated those participants who were able to complete the program? What role did receiving a diagnosis of cancer and their experience of cancer treatment, play in participants' understanding of their sexual difficulties and what influence did participating in OPES have on their understanding of their sexual self-perceptions, lives and relationships after cancer?

The purpose of this study was to gain a more in-depth and comprehensive understanding of women's experiences of working through the 12 module of the OPES online psychoeducation intervention aimed at healing the sexual aftermath following the diagnosis and treatment of reproductive or colorectal cancer. As a sub-study to the OPES study, I will be conducting in-depth, qualitative interviews with female participants who completed the OPES program and all assessment points (pre-, post- and 6 month follow-up). Women were chosen as the subject sample for logistical reasons – among those participants who were approached about this research, an insufficient number of men indicated interest in participating compared to women. The questions that guided this narrative inquiry were: ***How did women experience the OPES online psychoeducational program for sexual difficulties after cancer treatment, and what changes did they experience in terms of their sexual lives and relationships, during and following completion of the program?***

An in-depth exploration of the experiences of women who completed the OPES program will begin to provide a deeper understanding of the changes in women's sexual lives and relationships throughout, and following completion of the program. Important information will also be gained about the challenges women experienced in completing the tasks, exercises, and homework assignments required in the program. It is also intended that this study will illuminate some of the challenges that researchers and clinicians faced in running the OPES study, and will provide important contextual information to help in the interpretation of the results of our quantitative analyses. Obtaining information about the lived experiences of women who completed this online psychoeducation intervention will be extremely useful in informing us on how we can better meet the needs of those who have survived cancer and want to improve their sexual lives and relationships, in the aftermath of cancer treatment.

Chapter 2: Literature Review

Introduction

Sexuality is understood to be a fundamental aspect of human life. As was discussed in the previous chapter, sexual problems are common and distressing sequelae of cancer treatment for many survivors, that can persist years after cancer has been treated and can impact various aspects of an individual's quality of life (QoL). Treatment studies that focus on psychoeducational interventions aimed at improving sexual sequelae after reproductive and colorectal cancers provide moderate support for their effectiveness, although the available evidence for colorectal cancer patients is extremely limited. The Online Psychoeducation for Sexual Health in Cancer Survivors (OPES) program is one such intervention that offers additional evidence of the potential usefulness of such interventions. This review will first focus on the psychoeducational treatment literature which has informed the development and assessment of the OPES program. The second part of this chapter will detail the OPES study and its quantitative findings. These treatment studies have largely used quantitative approaches to determine the impact that psychoeducational interventions have had on ameliorating psychosexual difficulties among individuals who have been treated for reproductive and colorectal cancer. Appendix A contains a list of relevant outcomes measures used in the studies being reviewed. A brief summary of the limitations of relying solely on quantitative findings to determine program efficacy will follow, along with the identification of current gaps in our knowledge of what may promote and hinder treatment success among this population. The intention of this review is to highlight the need for implementing qualitative approaches in order to deepen our understanding of how survivors of reproductive and colorectal cancer survivors experience psychoeducational interventions, such as the OPES program, in assisting them in

achieving sexual wellbeing after cancer.

Psychoeducational Interventions Addressing the Sexual Sequelae of Cancer Treatment

Guerney, Stollak, and Guerney (1971), who have been credited as being among those who founded the psychoeducation movement (Authier, 1977), described psychoeducation as such:

The practicing psychologist following an educational model is one whose work would derive directly or indirectly from a concern not with “curing” neurosis and not with eliminating symptoms (or complaints) and not with intellectual growth per se but rather with the teaching of personal and interpersonal attitudes and skills which the individual applies to solve present and future psychological problems and to enhance his satisfaction with life (p. 277).

More recently, Lukens and McFarlane (2004) define psychoeducation as a professionally delivered treatment modality that integrates and synergizes psychotherapeutic and illness-specific educational interventions. Psychoeducational interventions targeting sexual difficulties after cancer may be most advantageous as when they reflect a bio-psycho-social conceptualization of sexual health and wellbeing. This review will present a variety of psychoeducational interventions that vary in their focus (i.e., addressing global psychosocial functioning or menopausal symptoms versus sexual functioning specifically) and include any or all of the following elements: education, therapy/counselling, skill-based training, supportive counselling or group therapy, and sex therapy. Interventions have been delivered to individuals, groups, or couples and have taken place either in-person, over the telephone, or over the Internet. These interventions also vary on whether or not sexuality was the main or a secondary focus. Considering the OPES study is a new addition to the ever-evolving treatment literature, this review will be organized based on the following elements that have been found to be important

in psychoeducational interventions aimed at healing the sexual aftermath of cancer: education plus skills-based training, elements of sexual therapy, and mindfulness (Brotto, Yule & Breckon, 2010; Taylor, Harley, Ziegler, Brown, & Velikova, 2011), plus evidence from similar interventions that have been offered in an online format.

Psychoeducational interventions focused on skills-based training. When reviewing the psychological intervention literature it becomes apparent that incorporating psychoeducation with skills training is important in producing improvements in sexual health after cancer treatment. While providing sexual health information after cancer is extremely important, it has been determined that providing education alone is ineffective in producing behavioural change (Brotto et al., 2010; Robinson, Faris, & Scott, 1999). For example, although vaginal dilation is the primary recommended therapy for women after radiotherapy for gynaecological cancer to prevent vaginal scarring, adhesions or stenosis, compliance rates are extremely low (Jeffries, Robinson, Craighead & Keats, 2006). To address this problem, Robinson and colleagues (1999) developed a group psychoeducational intervention (PED) based on an information-motivation-behavioural skills model to assist women with overcoming their fears of using vaginal dilators and to teach them behavioural skills to facilitate dilation compliance. Thirty-two women were randomized into either the PED, consisting of two 1.5-hour sessions, or the control group (written information and brief counselling). Women younger than 50 years in the PED were found to be significantly more likely to follow recommendations for vaginal dilation compared to the younger women in the control group, but the PED did not increase compliance among older women. While no effect of the PED was observed on global sexual functioning, women in the PED reported significantly less fear about resuming sexual activity compared to those in the control group.

In a more recent randomized control trial (RCT) with 42 sexually active women with cervical or endometrial cancer, Jeffries et al. (2006) found a brief therapist-initiated telephone call (3 weeks post-radiation) addressing women's unanticipated barriers around dilator use, in addition to the PED, significantly enhanced dilator compliance up to 6 months. Group differences did not remain statistically significant after 6 months, however, and dilation rates dropped in both groups to zero by the 18-month follow-up. Unfortunately, no data were collected on levels of sexual activity or satisfaction, relationship status, or women's levels of motivations for following through with rehabilitative vaginal dilation prior to, or following the interventions.

A rare exploratory qualitative study investigating women's experiences with vaginal dilators was conducted to understand what psychosocial factors influence women's willingness to follow vaginal dilatation recommendations after radiation treatment for gynaecological cancer (Cullen et al., 2012). Their analysis revealed that the majority of women in their sample of ten (average age was 52 years old) found dilator use embarrassing. Most also said it reminded them of the invasive and aversive experience of their cancer treatment and that it was not always seen as a priority to their recovery. What was interesting was how a majority of women found their own individual strategies for following through with dilation despite these barriers (e. g., using self-talk, creating various rituals, reframing the definition of dilator, and engaging in distracting activities during dilation such as reading). In sum, Cullen et al., concluded rehabilitative vaginal dilator use was a "a complex, multifaceted, and personal phenomenon that carries deep psychologic and emotional implications..." (p. 1170). This quote could easily be used as a definition for understanding sexual wellbeing and would be helpful to bear in mind when assessing the efficacy of any intervention aimed at healing the sexual aftermath of cancer.

Cullen et al.'s (2012) important qualitative investigation provides health care providers

with a deeper understanding into women's experiences of rehabilitative vaginal dilation and the challenges women face in following recommendations for maintaining their sexual health, as well as how some are able to overcome these barriers and others not. This serves as a good example of how qualitative inquiry can be helpful in building more effective interventions in addressing women's sexual health needs - something which to date, has rarely been included in studies to evaluate the effectiveness of these psychoeducational interventions.

General psychological therapy or counselling have not been found to be effective in improving sexual wellbeing among women who have received treatment for reproductive cancers, however counselling-based interventions that include psychoeducation plus skills-training have been found to be more effective (see Taylor et al., 2011). Marcus et al. (2010) demonstrated that early stage breast cancer survivors participating in their counselling intervention (n=152) had significant improvements in their sexual functioning from baseline up to an 18-month follow-up compared to the no-treatment control group (n= 152) that showed virtually no changes from their baseline sexual scores. Their intervention consisted of 16 telephone sessions with psychosocial oncology counsellors that focused on improving women's psychosocial problems over a 12 month period and also included progressive relaxation training, stress management, cognitive-based and emotion-focused worksheets, and information on community resources. Marcus et al. found that while depression and distress scores in both groups significantly dropped from baseline with no significant between-group differences, between-group differences showed significant improvements in sexual functioning (as measured by the Sexual Dysfunction Scale (SDS)) from baseline at both the 12- and 18-month follow-up, although the effect size at 18 months was small (0.23). A majority of the intervention group rated the support provided through the telephone counselling as being "most helpful," underscoring

the importance of more personalized contact. That said, participants also appeared to have a high level of engagement with the printed materials and the stress management techniques, that likely contributed to the apparent effectiveness of this intervention.

One shortcoming of this study was the small effect size of improved sexual functioning. Marcus et al. (2010) explained that the low effect size observed could be attributed to the lack of imposing sexually-related distress in the eligibility criteria, which suggests that participants' levels of sexual distress pre-treatment is an important variable to take into consideration when developing and assessing psychoeducational interventions and programs. As this intervention targeted more global psychosocial functioning rather than sexual difficulties specifically, it is difficult to ascertain in what ways this intervention adequately addressed participants' *sexual* concerns, and whether or not sexual difficulties were a major concern for those involved. A notable strength of this study was the large sample size, which is rare among psychoeducational intervention studies aimed at this population. The 16-session program also had a fairly high completion rate of 75% (n=114), and of those who dropped out of the program, the majority did so after only one session (44%), or after session 2 or 3 (36%). This suggests that the program was helpful in filling an important need among this population of breast cancer patients.

Peer support has also been found to be helpful with many psychoeducational interventions, although it remains extremely unclear whether peer support is what women find helpful in addressing their sexual concerns or again, whether information itself is what is helpful. Schover and colleagues (2006; 2011) investigated the benefits of a culturally sensitive, structured peer-counselling program among African American breast cancer survivors who were a minimum of 1-year post diagnosis and had completed treatment (exception was hormonal therapy). This intervention, called SPIRIT (Sisters Peer Intervention in Reproductive Issues after Treatment),

was designed to improve sexual function, decrease menopausal symptoms and infertility-related distress, and increase knowledge about reproductive health through three biweekly 60-90 minute in-person individual sessions with a peer counsellor. Sessions focused on one of three workbook chapters that was the most relevant to each woman: Menopause and Breast Cancer (i.e., hot flashes, vaginal dryness, and talking to your doctor); Sexuality and Breast Cancer (i.e., feeling unattractive, talking to your partner, resuming sex, low sexual desire, and sexual pain, dating); and Cancer and Your Family (i.e., fertility, safety of pregnancy, health of offspring, recognizing familial breast cancer, genetic counselling, and becoming an advocate for cancer screening).

In the pilot study, 30 women were randomized each into either peer counselling or waitlist control (mean age was approximately 54 years) (Schover et al., 2006). Women in the peer counselling showed significant improvements in their: levels of emotional distress (measured via the Brief Symptom Inventory-18 (BSI-18)), menopause symptoms (hot flashes) (via the Breast Cancer Prevention Trial (BCPT) Menopause Symptom Checklist), knowledge about reproductive health, and global sexual function (via the Female Sexual Functioning Index (FSFI)), although effect sizes for sexual functioning were quite small (0.14) calling into question the clinical significance of this finding. No changes were noted on any of these dimensions for those in the 3-month waitlist control. The authors noted that participants who were sexually “dysfunctional” at baseline (below the FSFI clinical cut-off ≤ 26.5) had much higher distress scores but became markedly less distressed by the 3-month follow-up. While Schover et al. suggest this drop in distress could be due to increases in women’s knowledge and self-efficacy, this finding could also be related to the fact that 47% of their sample lacked a current sexual partner (and may not have been sexually active), and may have had high degrees of distress around resuming sexually activity with a new partner after cancer. Because the researchers did

not impose sexually-related distress criteria on eligibility, we also do not know to what extent sexual functioning was a distressing concern for the women who participated in this study. Despite these shortcomings, this intervention highlights the importance of including relevant cancer and sexual health information in these types of interventions, as this was rated as being very useful by 81% of participants. Almost all rated the workbook as very easy to understand (94%) and their counsellor as very knowledgeable (96%) and very skillful (98%) (Schover et al., 2006).

Results from their nationwide RCT comparing 151 breast cancer survivors assigned to SPIRIT versus 146 who were randomly assigned to the workbook and ≤ 30 minutes of telephone counselling (to be initiated by the participant), provides further evidence that information is crucial in helping reproductive cancer survivors heal sexually (Schover et al., 2011). The benefit of additional peer support is more equivocal. Participants completed the same battery of questionnaires as was used in the pilot study. These outcome measures were administered at baseline, after the 6-week treatment period, and at 6-month and 1-year follow-up in. There were no significant between-group differences found across time but results from mixed-model analyses using all women in the sample ($n = 291$ participants at baseline and $n = 184$ participants at 12-month follow-up) showed significant improvements in knowledge about breast cancer and reproductive health, decreased distress and decreased hot flashes. No changes were found across time in FSFI scores, however, in exploring *only* those women who were sexually active at all assessment points ($n = 115$), FSFI results indicated improvements in sexual functioning at 6-month follow-up, but this was not maintained at the one year post-intervention. Again FSFI scores remained under the clinical cut-off at all time points suggesting ongoing sexual difficulties among this sample of women. Interestingly, among women who had a committed

partner, both relationship satisfaction and strong spirituality contributed to better FSFI scores (Schover et al., 2011). This suggests that women in satisfying relationships and/ or who have a strong sense of spiritual wellbeing (or a sense of purpose, meaning and comfort as measured by the items in the Functional Assessment of Chronic Illness Therapy, Spiritual Wellbeing subscale (FACIT-Sp)) may benefit most from such interventions.

While very promising, these results need to be considered in light of this study's shortcomings: attrition was higher in the nationwide study (28.3% from baseline to posttreatment and 38.3% by 1 year) compared to the pilot (20% from baseline to 3 month follow-up), and the program was rated *very useful* by only 66%, compared with 81% of women in their pilot study. Schover et al. (2011) speculated that these differences might have been due to decreased quality control in the study run at a national level. Taking into account that only 22% of the women utilized the telephone counselling, and that women in this condition gained as much as those who received peer counselling, it appears that the information provided in the workbook itself could account for the most benefit observed in this intervention (Schover et al.). It is not clear what impact psychoeducation may, or may not, have over the counselling and support provided in these interventions, in assisting women with their sexual difficulties.

In a comprehensive and individually focused intervention, Ganz et al. (2000) tested a “comprehensive menopausal assessment” (CMA) to relieve moderate to severe treatment-related menopausal symptoms, believed to impact sexual wellbeing among 37 women (average age of 54.5 years) treated for breast cancer, compared to a usual-care control group (n = 39, of which 4 dropped out). The authors referred to the control group as “usual-care” rather than no-treatment as patients were not precluded from obtaining treatment for their symptoms outside of the study, although they were not encouraged to do so. The CMA intervention consisted of a structured,

initial assessment of three target menopausal symptoms (hot flashes, vaginal dryness, and urinary incontinence), followed by an individualized plan of education, counselling, pharmacologic and/or behavioural interventions, psychosocial support, referrals, and follow-up tailored to each woman's individual needs and preferences. While experiencing sexual difficulties was not an inclusion criterion, women in this study indicated moderate problems with sexual functioning at baseline (Ganz et al.). Ganz and colleagues found that women in the CMA group showed significant improvements in menopausal symptoms and all 8 items of the Cancer Rehabilitation Evaluation System (CARES) Sexual Summary Scale compared to significantly improved arousal and orgasm only among women in the usual-care control group. The fact there was no attrition in the CMA group, very uncommon among intervention studies, suggests that the CMA was a highly relevant and useful intervention for women. However, the 5% attrition in the usual-care group was also uncommonly low. Perhaps the CMA intervention's success could be attributed to one of its strengths - that each woman's sexuality was addressed in the context of her unique physical, psychosocial and relationship status and sexual problems were not only managed with vaginal lubricants and moisturizers, but also included information and referral to self-help and professional resources (Ganz et al.). A qualitative addition to this study may have illuminated whether addressing the more narrow conceptualization of sexual health (e.g., vaginal dryness or hot flashes) or the more inclusive and comprehensive approach of the nurse counsellors, was what contributed to the improvements observed on the CARES scales (Ganz et al.), again highlighting the potential value of conducting post-intervention interviews.

Further evidence supporting the usefulness of addressing sexual wellbeing from a bio-psycho-social approach has also been borne out in treatment research with gynaecological cancer patients. Maughan and Clark (2001) implemented and investigated the efficacy of a specialist

nursing intervention focused on improving 19 women's quality of life (QoL) and sexual functioning following major pelvic surgery (mean age 50) compared to a "care as usual" control group of 17 women (mean age 48). In the entire sample, 13 women had not been sexually active in the year previous to their diagnosis. Women receiving "care as usual" received standard pre-trial information only (information, advice, support and referrals were only provided in response to a patient's request for information). Women in the nursing intervention group were seen by a clinical nurse specialist prior to surgery and later at their homes for an average of 3 sessions (no maximum). Six partners also agreed to participate in the women's rehabilitation. The nursing treatment included: emotional support; information regarding diagnosis and treatment; facilitation of communication between partners, social network and health professionals; and promotion of coping strategies. The nurse also discussed the effects of surgery on sexual functioning as appropriate, and provided information and advice on resumption of sexual activity.

The widely used European Organization for Research and Treatment of Cancer (EORTC) QLQ C30 and the less known Lasry Sexual Functioning Scale for Breast Cancer Survivors were completed pre-surgery and at 6, 12 and 24 weeks afterwards. Maughan and Clark (2001) observed a non-significant trend towards improved emotional, cognitive, social, and sexual functioning, better global health, and less sleep disturbance which continued to improve over six months for those assigned to the nursing intervention. While sexual functioning improved in both groups over six months, the intervention led to a quicker resumption of sexual intercourse, more frequent sexual activity, higher libido, and little to no anxiety related to intercourse, compared to those in the control group. Of note, 60% of women in the control group reported decreased satisfaction with intercourse 6 months following surgery, compared to only 20% of women in the

treatment group. These results are even more impressive considering that more women in the nurse intervention group required adjuvant pelvic radiotherapy compared to the women in the control group (20% and 5%, respectively), which likely reduced their QoL and exacerbated their sexual functioning difficulties.

Semi-structured interviews conducted at 6 months post-surgery with 20 women (7 from the nursing intervention and 13 from the control group), revealed that the sexual functioning scale used in this study, did not appear to target what seemed, from the women's feedback, important to measure (Maughan & Clark, 2001). The meaning of sexuality for these women was very much influenced by their relationship with their partners, the physical impact (i.e., altered anatomy) of their cancer treatments that affected vaginal penetration, the social and psychological impact of infertility and inability to have children, and any sexual problems they had been experiencing prior to surgery. Maughan and Clark concluded that these domains should be included in scales measuring sexual functioning, particularly when being used in cancer research. This study provides another good example of the importance of including, when possible, qualitative feedback from the participants who are involved in treatment research.

Similar to Ganz et al. (2000), Maughan and Clark's (2001) study did not suffer from high attrition (no dropouts aside from two deaths) compared to the majority of other sexuality focused, post-cancer intervention programs. Perhaps the individualized approach in both studies, focused on responding to the unique needs of each participant, helped reduce attrition, and contributed to the observed improvements. The higher attrition rates in most group interventions (discussed below), lends further support for a more individualized approach to psychosexual intervention programs for cancer survivors.

That said, there is some evidence that group interventions can also be helpful in improving

sexual health after cancer. In a nonexperimental design, Caldwell et al. (2003) pilot tested a structured 12-week psychosexual group therapy intervention focused on improving sexual functioning and reducing mood disturbances among 21 women who had received medical treatment for gynaecological cancer and were seeking help for their sexual problems (mean age 47). The group therapy intervention addressed issues of body image and sexuality. Weekly topics included: communication with partners; dealing with loss of fertility; loss of, or surgical alterations to, areas of body associated with sexuality; and the residual effects of cancer treatment on desire and the ability to have sexual relations. A unique aspect of this group treatment included encouraging women to experience a variety of pleasurable activities in their daily lives. Participants were also encouraged to identify, question, and refine their sexual scripts (which involved exploring their unique cultural background and previous history). Group process was based on a supportive-expressive intervention model (see Spiegel & Classen, 2000). Sixteen women completed the full intervention and all three assessments. The attrition rate was 24%. Despite the small sample size, Caldwell et al. found their participants significantly improved in mood, sexual frequency and arousal immediately post-intervention, with a trend towards improved orgasm. By the 3-month follow-up however, significant improvements were only found in frequency of sex, with nonsignificant trends evident in terms of improved sexual arousal and sexual pleasure. It is likely these results are due to the small sample size since statistical trends in improved overall sexual functioning were observed. Also, the lack of control group makes it difficult to determine the extent to which the observed changes were the result of the intervention.

In sum, there is evidence supporting the benefits of psychoeducational interventions that include skills-based training or encourage sexual health promoting behaviours (e.g., vaginal

dilation) to help women with their sexual problems after cancer and its treatment. However, whether these types of interventions result in lasting behavioural change or sexual improvements remains equivocal. What these studies also have in common is that they include some sort of social support, either with a health professional, peer, or in a group setting. Unfortunately, we do not know whether this type of support provides additional benefits in psychoeducational interventions that include skills-training, or what type of support may be therapeutically superior. Considering the studies discussed here, it does appear that individualized treatments with a specialized health professional (e.g., Ganz et al., 2000; Jeffries et al., 2006; Maughan & Clark, 2001; Marcus et al., 2010) are much more successful in retaining participants. This suggests that these types of interventions may be better suited to meeting the needs of women dealing with sexual problems after cancer treatment. However simply looking at study attrition rates alone cannot support this conclusion. Considering the OPES program was an online intervention with minimal interpersonal support (via the research assistant or the online discussion board only), understanding the impact of social support, or lack of, on intervention effectiveness would be very advantageous in the future development of the OPES program and other psychoeducational interventions for improving sexual health after cancer.

In addition, the degree to which each intervention specifically targeted sexual functioning varied greatly. For example, to improve sexual wellbeing, Jeffries et al. (2006) focused on increasing rates of recommended vaginal dilation to improve vaginal health, and Ganz et al. (2000) focused on improving menopausal symptoms, while Caldwell et al. (2003) focused specifically on improving women's sexual functioning and mood. Studies also varied on whether or not they included women who were specifically distressed by sexual problems. This raises questions about the relevance each intervention had on improving women's sexual quality of life

specifically, and whether or not this was a priority or concern for these women in their survivorship.

Finally, it is difficult to fully understand the impact these interventions have on sexual wellbeing considering the aforementioned problems with some of the outcome measures used in the research. For example, only through qualitative interviews did Maughan and Clark (2001) discover that the Lasry Sex Functioning Questionnaire failed to measure what women revealed was relevant to their sexual experiences after cancer. The widely used FSFI has also come across scrutiny for its problems in the original scoring procedures (Meyer-Bahlburg & Dolezal, 2007) and more recent discussions on its flaws, along with the International Index of Erectile Functioning, have been debated (Forbes, 2014; Forbes, Baille, & Schniering, 2014; Rosen, Revicki, & Sand, 2014). Unfortunately, there are no alternative, as widely-used, sexual functioning outcome measures that match the positive features of the FSFI and IIEF (see Rosen, et al., 2014). As a result, we have insufficient information on how women experienced these types of interventions, or what impact these have had on women's sexual wellbeing aside from the physiology of sexual "functioning." This highlights the importance of collecting qualitative data in sexual health research whenever possible. Qualitative investigations would provide deeper understanding of what aspects of various psychoeducational interventions women found the most relevant, effective and helpful in healing their sexual lives after cancer.

Psychoeducational interventions including sexual therapy. It has been argued that it is critical to include specific aspects of sexual therapy to increase the efficacy of psychoeducational interventions aimed at healing the sexual aftermath of cancer and its treatment (Brotto et al., 2010; Taylor et al., 2011). Although there have been fewer studies on *psychosexual* interventions, the results are quite promising. For example, Capone, Good, Westie, and Jacobson

(1980) investigated the effectiveness of in-hospital, individually tailored counselling in improving psychosocial adjustment among 56 women newly diagnosed with gynaecological cancer versus the members of a control group ($n = 41$) that consisted of outpatients with the same diagnostic criteria as those in the intervention. The counselling intervention was modelled on crisis intervention and consisted of one individual counselling session scheduled prior to a woman's cancer treatment followed by a minimum of 4 sessions occurring during the patient's hospital stay. The counselling intervention addressed understanding treatment effects, shaping expectations, interpersonal relationships, encouragement of adaptive behavioural change, and retaining a wholistic concept of self (included self-esteem and femininity). A sexual rehabilitation component was added for women who were sexually active before their diagnosis (defined as having had intercourse at least once in the previous year). This addressed common gynaecological cancer-related sexual misconceptions and fears, as well as methods of coping with anxieties associated with resuming sexual intercourse. For those whose medical condition prevented them from returning to their prior sexual activities, realistic expectations, options and alternatives were discussed. Among the counselled group, 41 women were considered "sexually active" compared to 25 in the control group.

Capone et al. (1980) found that among partnered women who were not anatomically or medically restricted from having sexual intercourse, the counselled women were more likely to have resumed sexual intercourse (59%) than the women in the non-counselled group (20%) at the 3-month follow-up. Differences in sexual functioning remained statistically significant at the 6- and 12-month follow-up. By 12 months, only 16% of the counselled group compared to 57% of control had not returned to their usual frequency of sexual activity. Although this intervention can be applauded for covering the physical, inter- and intra-personal aspects of sexuality, the

outcome measurement of “sexual functioning” is extremely limited in assessing *frequency of intercourse*, but not assessing the women’s levels of *sexual satisfaction*. Therefore, with its focus on intercourse as the measure of change and success, it is difficult to fully appreciate the extent to which this intervention contributed to enhancing the participants’ overall sexual wellbeing. Gynaecological cancer survivors in heterosexual relationships may well engage in sexual intercourse despite physical pain and discomfort, in order to please their partner or relieve feelings of guilt (Gilbert, Ussher, & Perz, 2011).

Almost three decades later, Rowland et al. (2009) attempted to determine the efficacy of a psychoeducational group intervention (PED), by using the CARES, a more comprehensive, commonly used, reliable and valid measure of sexual rehabilitation and quality of life among people with cancer (Taylor et al., 2011). The PED program addressed persistent difficulties with body image, sexuality, intimacy and/or communication with a partner, using a subsample of 1084 breast cancer survivors that had been surveyed in a larger preliminary research study. Women who were randomized to the intervention (n=284) and the control group (n=127) had completed medical cancer treatments an average of 3 years earlier. The intervention consisted of six two-hour sessions designed to be useful for both partnered and unpartnered women. The sessions included structured educational, communication-training and sex therapy components (based on general principles of sensate focus therapy), aimed at improving satisfaction with sexual functioning and intimate relationships, and at reducing anxiety in intimate situations. An unstructured group discussion was also included in each session. Topics covered included body image and sexual anatomy, sexual attitudes and behaviours, menopause, sexual (dys)function, communication skills, sexual enhancement, and future goals. Women in the control group received a National Cancer Institute educational pamphlet called “Facing Forward: A Guide for

Cancer Survivors.”

It is important to note that only 29% of women randomized to the intervention group agreed to participate (n=83). Seventy-two of these women actually attended at least one session, and 11 did not attend any. Only a further 57 women (79%) returned the 4-month follow-up questionnaires and how many of these women completed all the sessions was not reported. Out of the 179 women who declined to participate in the group intervention after being randomized to the treatment, 129 (72%) provided follow-up data and were included in the analyses as intervention *non*participants. Of the 127 women who were randomized to the control group, 77% provided follow-up data. Rowland et al. found that women who participated in the group (M age = 53.4) were significantly younger than those randomized to the treatment group who did not attend the intervention (M age= 58.4) which may suggest that younger women may be more motivated to address their sexual problems compared to older women.

In order to account for any potential bias due to problems with study uptake and attrition, Rowland et al. (2009) conducted various statistical analyses to assess the efficacy of their program. From baseline to 4-month follow-up, the only significant changes in scores among intervention participants were a decline in pain with sex. Significant declines in mental health were observed among control and intervention *non*participants, as well as declines in satisfaction with sex and relationship adjustment in the control group, which were not observed among intervention participants. Results from anonymous group evaluations, indicated that a majority found the PED helpful in improving their sexual functioning and perceived it to be worthwhile. A large percentage of PED intervention participants (78%) indicated that they had at least partially met the sexuality and intimacy-related goals they had set for themselves during the group, and 87% indicated they had set new goals for the future (Rowland et al.). In sum, the

authors concluded that while no consistent findings were demonstrated for specific sexual outcomes in the various statistical analyses they performed, their evidence suggested this intervention can be beneficial in improving relationship adjustment and communication as well as increasing satisfaction with sex, especially for those who are highly dissatisfied with their sexual relationship (Rowland et al.).

A major limitation in Rowland et al.'s (2009) research is the extremely low uptake (25% of those randomized to treatment actually attended at least one group session) and high attrition (21-27% loss of respondents at follow-up). While this is not uncommon for intervention studies, Rowland et al. provided some useful information about their recruitment challenges and the potential barriers to participation that may address this common problem among the majority of treatment research on this topic, including the OPES program. For example, geographical distance, severe depression and very poor relationship functioning excluded a total of 39% of the 1084 women who returned baseline questionnaires in the initial survey. Reasons for declining participation in the intervention itself included inconvenient times and locations of the group sessions, not being distressed about sexual problems, and being too busy. During their intervention, many women were also unable to make the time commitment required to attend 6 two-hour meetings (Rowland et al.). Another possible shortcoming that could be related to the lack of treatment effect in this study is that six weeks may be too brief an intervention to create lasting change and longer interventions may be more effective in improving longer lasting sexual improvements (see Brotto et al., 2010). Delivery of this type of intervention in a group format has also been shown to be less effective in producing positive changes among breast cancer patients or survivors, compared to interventions targeted at individuals or couples (Taylor et al., 2011). Considering the geographical barriers, time commitment involved, and discomfort of

addressing personal sexual problems with others in group settings, that can prevent people from participating in such interventions, online interventions, such as the OPES program, may be more appealing for participants.

Both Capone et al. (1980) and Rowland et al.'s (2009) studies focused on specific treatment-related sexual concerns identified by survivors of reproductive cancers. These stand in contrast to the more common approach of improving global psychosocial functioning among women diagnosed with reproductive cancer who may or may not have sexual difficulties (Rowland et al., 2009). What is interesting about Rowland et al.'s results is that they provided evidence that relationship satisfaction and communication can be improved in the absence of including partners in these types of PED interventions. Capone et al. also provided evidence that individually focused interventions for partnered women can lead to improvements in sexual functioning. This is particularly important given that many cancer patients or survivors may not be partnered, many partners may not be interested in participating in such intervention studies, and that researchers face even further recruitment challenges when attempting to deliver these types of interventions to couples compared to individuals. Furthermore, these findings provide a rationale for not requiring partners of cancer survivors to participate in psychological interventions aimed at improving sexual health after cancer treatment, as was the case with the OPES study.

While evidence from these two studies, and intuition, suggests that including elements of sexual therapy is a necessary component in psychoeducational interventions treating sexual sequelae of cancer treatments, there is not sufficient evidence to conclude this adds additional benefit. Again, qualitative interviews with participants would help us understand what participants' attitudes are towards sexually oriented exercises, how helpful are they to one's

sexual wellbeing, and what challenges can arise when completing exercises specific to sexual therapy (e.g., sensate focus exercises).

Mindfulness-based psychoeducational interventions. Mindfulness practice originates from ancient Eastern philosophy and Buddhist meditation and has been increasingly embraced by Western healthcare and psychology over the past four decades (Austin, 1998; Black, 2011). A widely recognized Western definition of mindfulness is “paying attention in a particular way: on purpose, in the present moment, and non-judgementally” (Kabat-Zinn, 1994). Mindfulness has been incorporated into various interventions and has been well received by participants for chronic illness, mental illness, stress, behavioural problems and pain (e.g., Baer, 2003; Kabat-Zinn, Lipworth, & Burney, 1985). Mindfulness interventions have been found to have lasting effects in reducing anxiety, depression, and stress and improving quality of life (Khoury et al., 2013). A review of mindfulness-based stress reduction interventions for cancer patients revealed improved sleep, mood and stress reduction (Smith, Richardson, Hoffman, & Pilkington, 2005). Because mindfulness practice involves being aware of and focusing in on one’s own body in the present moment, and letting go of expectations, it could be applied to sensate focus exercises and sexual scenarios, thereby having the potential to help women with their sexual problems (Brotto & Heiman, 2007). Brotto and Heiman (2007) proposed that incorporating mindfulness in the development of psychoeducational programs for women with sexual difficulties after gynaecological cancer could be promising.

Although the research is limited, evidence suggests that mindfulness indeed can be an effective and well-received component of psychoeducational interventions for women with sexual complaints following gynaecological cancer (Brotto & Heiman, 2007; Brotto et al., 2008; 2012). A brief face-to-face structured psychoeducational intervention (PED) that incorporated

skills-training in mindfulness meditation along with education, cognitive behavioural therapy, and elements of sex therapy has been found to be efficacious in both the pilot study (Brotto et al., 2008) and a later wait-list control study of the same PED (Brotto et al., 2012). The focus of this PED was on evoking sexual awareness and teaching arousal-enhancing techniques, in order to assist partnered women treated for cervical or endometrial cancer in improving: sexual response (arousal, orgasm, sexual desire), sexually-related distress, relationship satisfaction, depressive symptoms, and quality of life (QoL). One strength of both these research protocols was enrolling only those women who were experiencing distressing low sexual arousal and/or desire that they associated with their cancer treatment. The PED consisted of three monthly 90-minute individual face-to-face sessions, plus informational handouts for participants including exercises to complete over the following month. Aspects of the PED were adapted from a variety of sources, including an empirically supported behavioural treatment for women with lifelong orgasmic disorder called *Becoming Orgasmic* (Heiman & LoPiccolo, 1988), *Seven Principles for Making a Marriage Work* (Gottman & Silver, 1999), the *Miracle of Mindfulness* (Nhāt Hahn, 1987), and *Progressive Relaxation* (Jacobson, 1938) (see Brotto et al., 2008).

In the pilot PED (Brotto et al., 2008), the mean age of the 22 participants was 49.4 years (range 26-68), their mean relationship duration was 15.3 years (range 1-45 years), and the mean time since cancer surgery was 54 months (ranged from 6 to 115 months). Several measurements comprised the questionnaire battery administered prior to the first session and following session four (see Appendix A), including individual physiological and subjective sexual arousal assessments.

Brotto and colleagues (2008) found the PED was effective in decreasing sexual distress and increasing levels of sexual desire, arousal, orgasm, and satisfaction, as well as general sexual

functioning (FSFI total score). However, no significant changes were found for genital lubrication or pain. Women also reported increases in subjective sexual arousal (i.e., perceived genital arousal and mental arousal) when exposed to an audiovisual erotic stimulus, although these findings were not statistically significant. Women also reported improvements in relationship adjustment although this did not quite meet statistical significance. Significant decreases in depressive symptomology were also observed with women with higher depression scores showing a greater reduction in depressive symptoms compared to women with lower depression scores. Women in this PED were extremely compliant with the suggested homework exercises, with self-reported compliance ranging from 82% to 90% across the three sessions (Brotto et al.).

The addition of a qualitative component also provided important information about participants' experience of the program. Semi-structured interviews conducted with participants indicated that all the women found the PED beneficial and were pleased to have participated. Many also reported they were more hopeful about their sexuality since completing the program (Brotto et al., 2008). There was also unanimous consensus that sexuality was important after cancer and that these women would have welcomed the information provided in the intervention, earlier in their cancer treatment. Furthermore, the intervention helped some women to see their bodies in a more positive light (Brotto et al.). More specifically, women also reported that the mindfulness segments of the intervention were particularly helpful as it encouraged them to tune into remaining genital arousal and resulting pleasure that they thought was gone after their cancer treatment. Many wished they had learned the practice much earlier in their lives (Brotto & Heiman, 2007).

Similar positive quantitative results found in the control trial provided further support for

the efficacy of this PED (Brotto et al., 2012). In this latter sample, the mean age for the 31 participants (n = 22 in the immediate treatment (IT) versus 9 in waitlist control (WL)) was 54 years (range 31-64), relationship duration was 22.1 years, and mean number of years since cancer surgery was 4 (range 0.6 to 22 years). Brotto et al. (2012) used a similar but shorter questionnaire battery as the pilot study which was administered at baseline (before women were placed into the IT or WL group), at 3-months for the WL group only (before starting the PED), after receiving the PED, and 6-months post-PED. No significant changes were found in the treatment time period for women in the WL group before receiving the PED. Women in the PED (n=31) revealed significant improvements in sexually-related distress, sexual arousal, desire, lubrication, satisfaction and sexual functioning (FSFI) total scores – improvements that were maintained to the 6 month follow-up suggesting long-standing effects. There were no changes in reported levels of sexual pain. No significant improvements were found in the *relationship* or *treatment impact* domains of the Sexual Function Questionnaire or depressive symptoms. However, those women with high depression scores showed an overall greater reduction in their depressive symptoms compared to those with lower scores. In addition, the PED was also seen to lead to a significantly greater increase in perception of genital arousal when exposed to erotic stimuli, meaning women were more likely to notice signs of physiological sexual arousal (i.e., genital throbbing and lubrication) when exposed to erotic stimuli compared to pre-PED. This, including similar results found in the pilot, suggested that there is an additional benefit of including mindfulness skills in these interventions. One shortcoming of this study, however, is that a waitlist control group does not allow for control of non-specific therapeutic factors that may have contributed towards improvement such as receiving information or increased attention to sexual wellbeing (Brotto et al., 2012).

Similar to the majority of other interventions for cancer survivors, Brotto et al.'s research (2008; 2012) also suffered from low uptake of participants in both the pilot and later waitlist control study (response rate to invitation was 18.5% and 28.7%, respectively) and attrition (37% and 9%, respectively). The primary reasons reported for declining participation were similar in both studies and included: related to geographical distance from care centre (50%) as well as burden of numerous testing sessions, discomfort over the arousal assessment, and difficulties talking about sexuality (Brotto et al., 2012). In consideration of these participation rates, this program may benefit a small and select group of gynaecological cancer survivors who report experiencing distressing low desire and arousal difficulties that they attribute to their cancer treatment. Furthermore, many women declined participation due to discomfort with the arousal assessment (Brotto et al.). Therefore, women who were willing to undergo a potentially invasive assessment as the physiological arousal assessment may be qualitatively different from women who may be uncomfortable with such procedures (i.e., more sexually open-minded or comfortable with her body, genitals or sexuality), making it difficult to make generalizations to greater cancer population.

Despite the small sample sizes, the results of these two studies suggest not only that this brief mindfulness based PED was effective in improving sexual functioning and awareness of sexual arousal but also that the benefits were longstanding (Brotto et al., 2008; 2012). It is important to note that these two studies are the only known trials to focus on specific sexual complaints of low sexual desire and impaired sexual arousal among survivors of gynaecological cancer that were also reported to be distressing for the woman and/or her relationship.

In sum, mindfulness appears to be a useful addition to psychoeducational interventions that incorporate sexual therapy such as sensate focus. In fact, women reported mindfulness as being

the most helpful aspect of the PED (Brotto & Heiman, 2007). As will be discussed later in this chapter, considering geographical distance was reported to be a major barrier preventing women from participating in this PED, administration of such programs in an online format would increase accessibility of psychoeducational interventions for sexual difficulties among cancer survivors (Brotto et al., 2008; 2012)

Couples-based interventions for colorectal cancer patients. For survivors of colorectal cancer, health care providers can be an invaluable resource for providing relevant information and support on managing the potentially emotional distressing effects of an ostomy on sexual functioning/ activity and can offer strategies to minimize such undesirable effects as odour, gas, stool leakage, and gastrointestinal upset (Altschuler et al., 2009; Ayaz & Kubilay, 2009; Black, 2004; Varela, Zhou, & Bober, 2013). However, research on interventions to manage sexual problems after treatment for colorectal cancer remains scarce (Varela et al., 2013). The only known treatment studies examining the efficacy of psychologically-oriented interventions for colorectal patients, or intestinal cancer survivors with a stoma, were interventions aimed at couples (Ayaz & Kubilay, 2009; Reese, Porter, Somers, & Keefe, 2012; Reese et al., 2014).

Research indicates that partner or spousal support is extremely important in the psychosocial and psychosexual adjustment of cancer and its treatment effects (i.e., Altschuler et al., 2009; Baucom et al., 2009; Manne & Badr, 2008; Scott & Kayser, 2009). However, research with couples face significant challenges in securing the participation of both members of each couple compared to enrolling a single member. While there is evidence suggesting that psychosocial interventions that include the cancer survivors' partners are more effective than those that do not include significant others (Manne & Badr, 2008; Scott & Kayser, 2009; Taylor et al., 2011), the findings are inconsistent (see Nelson & Kenowitz, 2013). As previously

discussed, some interventions targeting the individual have been found to have positive effects on relationship satisfaction and communication even if the partner is not present in the intervention (e.g., Rowland et al., 2009). However, psychoeducational interventions involving spouses also have been found to be effective, especially among colorectal cancer survivors and cancer patients coping with an ileostomy or colostomy.

Reese and colleagues (2012; 2014) are the only known researchers to investigate a psychosocial treatment targeting sexual concerns among colorectal cancer survivors, and involved spouses in their intervention. In contrast to the other PEDs reviewed here, rather than focusing on alleviating sexual “dysfunction,” their telephone-based *intimacy enhancement* (IE) intervention focused on enhancing *intimacy* which was defined as “an interpersonal process involving mutual sharing and understanding, feelings of closeness, warmth and affection” (Reese et al., 2012, p. 403). The IE intervention consisted of four weekly 50 minute phone-based sessions focused on teaching couples behavioural skills for coping with sexual challenges and improving both physical and emotional intimacy. The IE intervention included techniques from sex and marital/couples therapy (i.e., sensual touching exercises), improving sexual communication, identifying and challenging overly negative or inflexible sexually-related cognitions, and broadening their repertoire of both sexual and nonsexual intimacy-building activities. Each telephone session followed a detailed agenda and focused on a specific skill, and behavioural exercises were explained and assigned for practice.

In Reese et al.’s (2012) pilot feasibility study, 14 couples were consented (out of 45 patients who were initially screened) to participate in the IE intervention. Two couples dropped out before the first session, one couple was lost to contact after having provided consent, one couple dropped out after one session due to cancer recurrence, and one couple completed all four

IE sessions but failed to return the post- intervention questionnaires. Nine couples who completed all sessions and assessments were included in the analysis of intervention efficacy. Pre/post effect sizes were conducted separately for patients and partners from a battery of sexually related outcome measures (see Appendix A). Results from *patient* data revealed large effect sizes for sexual distress, female sexual functioning, and sexual communication; medium effect sizes for dyadic adjustment; and small effect sizes for intimacy. Sexual functioning for male patients showed little improvement. For *partners*, large effect sizes were observed for female sexual functioning, and medium effect sizes for sexual distress, sexual communication, intimacy, dyadic adjustment, and male sexual functioning. A majority of participants (83%) rated the IE intervention as quite easy to participate in and helpful, that it met their expectations, and was believed to an important program for people with colorectal cancer. Also, 72% reported that the intervention was quite helpful in improving intimacy in their relationship. While these results show promise for such an intervention in improving sexual intimacy among couples where one partner has been treated for colorectal cancer, the effect sizes need to be interpreted with caution considering the very small sample size and lack of control group.

In a follow-up controlled trial, Reese et al. (2014) randomized to either the IE treatment or to a waitlist control condition (WL) 23 heterosexual couples with sexual concerns after one partner had been treated for colorectal cancer. Of the patients who were randomized to each condition (29% of 79 eligible patients initially screened), only 18 completed the study (10 in the IE group and 8 in the WL group) and were included in the data analyses (mean age was 52.6, relationship duration was 21.5 years, and months since diagnosis was 23.3). One particular strength of this research was that participants in the IE condition appeared to be highly motivated as attrition occurred only *before* the first session took place.

Unfortunately, the sample size again was too small to find significant effects for patients or to compare the effects of the IE intervention on sexual function by gender. However, data from a similar questionnaire battery as the pilot study revealed a number of medium to large effect sizes, suggesting the IE intervention may well have provided some benefit for both patients and their partners (Reese et al., 2014). Both male and female patients indicated improvements in their sexual functioning via the FSFI and IIEF (effect sizes of 0.58 and 0.85, respectively). For female patients, medical impact on sexual functioning (-0.66), and self-efficacy for enjoying intimacy despite physical limitations (0.66) also improved. No changes were observed in the patients' levels of sexual distress or intimacy and small negative effects were observed for sexual communication and two self-efficacy items (communicating and dealing effectively). Interestingly, the IE may have been more helpful for *partners* since they improved on all sexual and relationship outcomes, including sexual communication (with medium to large effect sizes), although the effect size for improved sexual functioning among female partners was minimal (0.18). Despite the lack of consistent treatment effects among patients, the IE intervention was rated favourably by both patient and their partners, in terms of its helpfulness (90%), ease of participation (65%), and relevance (70%), and a majority reported using the skills they learned within past two weeks (i.e., 100% reported using an intimacy-building activity in the previous 2 weeks). Interestingly, the two skills that appeared the *least* easy to use were “doing something to increase your sexual desire,” and “trying a strategy to solve a sexual problem.” This may have been related to the fact that half of the IE participants were currently undergoing treatment (chemotherapy and/or radiation) which is known to adversely affect sexual desire and arousal. Furthermore, the authors noted that the baseline scores for sexual distress, intimacy, and sexual communication in the 2014 IE sample were comparable to those found post-treatment in their

previous pilot study (Reese et al., 2012). This could suggest that this type of intervention may be more effective for patients experiencing higher levels of sexual distress. Finally, considering having an ostomy can result in an additional burden on sexual wellbeing (Black, 2004), there was a low percentage of patients in this study with past or current ostomy (11% and 22%, respectively) compared to their pilot intervention (22% and 33%, respectively out of n=9). This presents a potential problem in generalizing these results to a population of cancer patients coping with an ostomy. In sum, the authors concluded that the IE couples intervention has promise to be effective in improving multiple domains of both physical and emotional intimacy for colorectal patients and their partners, although further research is necessary (Reese et al., 2012; 2014).

In an intervention specifically aimed at assisting cancer patients with stomas, Ayaz and Kubilay (2009) found that their nursing intervention using the PLISSIT model (not manualized) was effective in helping address sexual problems for 30 intestinal cancer patients compared to 30 patients who did not receive the intervention. While this intervention was not described as a couples-based intervention per se, patients' spouses attended the nursing intervention and therefore could be considered as participating in their spouses' sexual recovery. Unfortunately, questionnaire data was not collected from spouses and it is unknown to what extent spouses actively participated in the intervention.

The treatment group received eight bi-weekly home visits by a trained nurse after discharge from the hospital, while the control group received one interview before hospital discharge and again four months later. Unfortunately, there was a significant difference between these groups that deserves attention – participants in the intervention group lived in Ankara, Turkey while those in the control group resided outside of the city. It is unknown how, if at all,

this difference may have influenced the results of this study. Considering patients who live outside major cities may face additional barriers to receiving outpatient support after cancer treatment, the treatment group may have received unanticipated additional benefits by living closer to their cancer treatment centre and city resources.

For the treatment group, Ayaz and Kubilay used the PLISSIT model to guide assessment of patient's sexual problems, make treatment recommendations or plan appropriate interventions in order to help solve patients' sexual problems. The PLISSIT model, commonly used in nursing, facilitates the discussion of sexuality with patients and helps determine sexual problems. The model provides a four-step approach: permission (P), limited information (LI), specific suggestions (SS), and intensive treatment (IT). The authors noted that the IT level of the model was determined to be unnecessary as all patients had resumed sexually activity and reported no major problems by the end of the intervention (Ayaz & Kubilay, 2009).

The mean age for both intervention and control samples was approximately 44 years of age. Seventy percent of the intervention group and 66.7% of the control group were male patients and all participants were married and living with their families. All participants were reported to have "an active sexual life" prior to their surgery. The Golombok-Rust Inventory of Sexual Satisfaction (GRISS) was used to determine quality of sexual intercourse and sexual dysfunction for men and women. The GRISS was administered to both groups prior to stoma creation, to the treatment group only at 6 weeks post-stoma creation, and again to both groups four months post-stoma creation.

Ayaz and Kubilay (2009) found that nearly every domain of sexual functioning for men and women improved in the treatment group from 6 weeks post-op to 4 months post-op, which is consistent with expectations about the resumption of sexual activity in cancer survivors post-

surgery. Among male participants in the treatment group sexual frequency, satisfaction, sensuality, premature ejaculation and impotence improved across all time points and avoidance of sexual activity was reduced among male patients. Among female participants in the treatment group, sexual satisfaction improved and avoidance and anorgasmia were reduced, although no improvements were seen in the domains of sexual frequency, sensuality, or vaginismus. No improvements were observed in communication for women or men in the treatment group. In contrast, sexual functioning deteriorated for both men and women in the control group from pre-op to 4 months post-op. A between groups comparison at the 4 month follow-up indicated members of the treatment group had significantly improved scores in most sexual functioning domains. However, no significant group differences were seen for communication and sensuality for men or women, impotence for men, and vaginismus for women. The authors also noted that after four months, more individuals in the treatment group were sleeping in the same bed as their spouse compared to those patients in the control group (93.3% versus 53.3%, respectively).

An important strength in Ayaz and Kubilay's (2009) PLISSIT intervention was that there was a 100% participation rate with no dropouts. This may suggest that the convenience of in-home interventions may increase levels of participation, and/or that there is a high need for health care support among cancer patients with an ostomy. Unfortunately, qualitative interviews or participant evaluations of the intervention were not included in this study.

Unfortunately there are no known individually focused or group psychoeducational interventions to help improve sexual wellbeing among colorectal cancer patients/ survivors with which to compare these two studies. This makes it difficult to make any conclusions on whether having partners participate in such interventions will result in greater sexual improvements for those who had colorectal cancer. Perhaps the difficulty in recruiting both members of a couple to

participate in this research can speak to the low uptake observed in both interventions. Considering a zero attrition rate was observed among participants who started either intervention, suggests that there is a high need among a subsample of this population for help with intimacy and sexual functioning after cancer treatment for colorectal or intestinal cancer. In fact, certain interventions such as that developed by Reese and colleagues (2012; 2014) may indeed be helpful not only for patients but their partners as well. There are some inconsistencies on the extent to which these two interventions were helpful in improving sexually related distress, male erectile functioning, and vaginismus among patients, as well as relationship communication and sensuality. Again, understanding how these interventions are experienced by both patients and partners would be extremely helpful in further developing interventions that can meet the needs of cancer patients/ survivors living with a stoma and to help them cope with the challenges these cancer treatments have on patients' intimate and sexual lives. It was the intention of the OPES program investigators to include this population and add to the intervention literature by examining the efficacy of the OPES program for colorectal cancer survivors.

Internet-based psychoeducational interventions for reproductive cancer survivors.

Considering that geographical distance may be a significant barrier, or deterrent, for accessing psychoeducational interventions and support, web-based interventions, accessible from an individual's home, would seem to be an advantageous and effective means to help cancer survivors who would otherwise be unable to access treatment services. A 2005 Cochrane Review of web-based interventions combining health information with at least one of social, decision, or behavioural-change support for people with chronic disease, found these online interventions had a significant positive effect on knowledge, social support, clinical outcomes, health behaviours

and self-efficacy (Murray, Burns, See Tai, Lai, & Nazareth, 2005). Among cancer patients specifically, the use of Internet-based psychosocial and support groups has grown rapidly over the past decade (see David, Schlenker, Prudlo, & Larbig, 2013). A pan-Canadian initiative known as CancerChatCanada (www.cancerchatcanada.ca) has demonstrated that the convenience and privacy offered through professionally-led online support groups, is effective in increasing patient, survivor and caregiver access to psychosocial services (Stephen et al., 2013). The Internet also is an important resource for cancer patients and survivors to locate helpful information on the sexual side effects of cancer treatments (e.g., Davison, Elliott, Berkowitz & Goldenberg, 2004).

Griffiths (2005) summarized the advantages of internet-based therapy compared to face-to-face interventions. The Internet has a disinhibiting effect on users and reduces social desirability, which in turn can increase user honesty and rates of self-disclosure. Because it is not face-to-face, the anonymity of participating in online therapeutic interventions can be far less threatening especially when these involve topics of a sensitive nature (Griffiths, 2005) such as sexuality. This suggests that online interventions targeting sexual concerns may be favourable in providing anonymity to cancer patients and survivors who are uncomfortable discussing sexual concerns face-to-face or in-group settings.

There is a lack of published research addressing the efficacy of online interventions specifically aimed at helping women with their psychosexual difficulties after reproductive cancer treatments, or for women and men with colorectal cancer. However, the few existing studies of online support efforts that specifically address sexual sequelae after these cancers indicate that they may also provide a safe and anonymous place for women to discuss their sexual problems. For example, *GyneGals*, has shown promise to be an effective Internet-based

psychosexual intervention according to the results of qualitative (Wiljer et al., 2011) and quantitative analyses (Classen et al., 2013) of data acquired from the same sample of participants. *GyneGals* was a 12 week, professionally moderated, support group focusing on weekly sexually-related topics/ information relevant to gynaecological cancer, based on Spiegel's supportive-expressive group therapy for cancer patients (see Spiegel & Classen, 2000). Since the focus of *GyneGals* was to reduce psychosexual distress, to be enrolled in the program women were required to score at least 24 on the Female Sexual Distress Scale- Revised (FSDS-R), indicating high clinical sexual distress. Twenty-seven women who had been diagnosed in the previous 5 years, had completed cancer treatments, were cancer free for up to 3 months, and were willing to discuss their psychosexual concerns were included in the pilot investigation of *GyneGals* (Classen et al., 2013; Wiljer et al., 2011). Thirteen women (mean age 39.9), the majority of whom were partnered (77%), were randomly assigned to the intervention group, while 14 women (mean age 44.6), the majority of whom were unpartnered (57%), were assigned to the waitlist control group. Women assigned to the waitlist condition received the intervention approximately four months following their baseline assessment (Classen et al., 2013; Wiljer et al., 2011).

The program consisted of professionally moderated *asynchronous* group discussions (participants could log on and post comments at any time) on the weekly topic or other topics determined to be important by the participants. A link from the discussion forum to a separate website that housed the program's psychoeducational material (covering information pertinent to each week's discussion topic) allowed easy access between the two forums. Weekly topics covered included: gynaecologic cancer treatments and side effects; emotional challenges; body image and self-identity issues; sexuality and sexual functioning; managing the impact on

intimate relationships; communicating with loved ones about cancer; dealing with early menopause; and management of symptoms such as pain, fatigue, vaginal changes, and incontinence. The intervention also included one 90-minute live-chat session with a gynaecologic oncologist, radiation oncologist, and the forum facilitators during week ten.

In order to determine the efficacy of their program, Classen et al. (2013) administered the FSDS-R, the Hospital Anxiety and Depression Scale (HADS), and the Illness Intrusiveness Ratings Scale (IIRS) at baseline (pre-treatment), after the immediate group completed the program (4-month follow-up), and again after the waitlist condition completed the intervention (8-month follow-up). Only 21 of the 27 participants completed the four-month follow-up questionnaires, reflecting a 22% program attrition rate. The authors opted to increase the sample size by sacrificing independence of scores and using data from both the treatment and waitlist control. No significant differences were found between the participants in the treatment and waitlist control group on any variables. However, preliminary analysis of pre/post treatment differences revealed medium effect size reductions in sexual distress, suggesting that this intervention may help to reduce sexually-related stress and enhance intimacy for this population (Classen et al.). Their additional exit questionnaire indicated the majority of participants reported that the information provided in the program increased their knowledge (60%). Sixty-seven percent of participants in the treatment group said they felt comfortable sharing their experiences in this on-line format, including their sexual concerns (60%). Of the 21 respondents, 12 (57%) indicated that they felt more comfortable discussing sexual issues in a web-based support group than they would in a face-to-face group, compared to six (29%) who indicated that there were less comfortable. (Classen et al.).

These positive responses confirmed prior results of the semi-structured interviews with 12

of the *GyneGals* participants (Wiljer et al., 2011). These women reported benefit from acquiring important information and receiving support, which results in enhancing their emotional wellbeing and overall quality of life, improving their feelings about their body image and sexuality, and increasing their comfort in discussing sexuality online (Wiljer et al.). These interviews also illustrated that 12 weeks was found to be an appropriate length of time for the intervention. Wiljer et al. found that while women reported that discussing sexuality was good – improving how they felt about their body and about being a sexual person – discussions about sexuality and intimacy were reportedly more helpful for the partnered women compared to the single women. It was also confirmed that the online format allowed participants to protect their anonymity and that this anonymity made it easier for the women to ask sensitive sexual questions online compared to face-to-face however sexuality still remained a difficult topic for some participants to speak about.

The major limitation of this study, not unlike other studies discussed here, was the small sample size and resulting insufficient power to obtain statistically significant differences between the treatment and waitlist control group. Despite recruitment challenges, the fact that about half the women who were approached about the study reported having interest in the study provides evidence that there is a lot of patient interest for supportive interventions addressing gynaecological cancer patients' sexual concerns (Classen et al., 2013). Another limitation in the *GyneGals* research was that the researchers were not able to track their participants' online behaviours so it was difficult to know what aspects of program participation were predictive of program benefit (i.e., the supportive element or receiving relevant information). However, the strength of the *GyneGals* study was offering potentially effective treatment opportunities for sexually distressed gynaecological cancer survivors to acquire both information and social

support in a program focused on a comprehensive bio-psycho-social approach to restoring and enhancing sexual wellbeing after cancer and its treatment.

Another recent RCT of an internet-based intervention for female sexual dysfunction related to reproductive cancers, suggests that Internet-based interventions can help improve sexual difficulties and satisfaction among women who have survived reproductive cancers several years after cancer treatment (Schover et al, 2013). The program, *Tendrils: Sexual Renewal for Women after Cancer*, also was a 12-week intervention designed to provide women who reported high levels of sexual dysfunction (scoring ≤ 26.5 , the clinical cutoff on the FSFI) and their partners, with information about cancer-related sexual problems and medical treatment options, how to find and access expert care, and self-help strategies in order to improve sexual function and satisfaction. Of the 72 women who consented to participate, half of whom were randomly assigned to receive the internet-based intervention as self-help (n = 36), or the same intervention with 3 supplemental in-person counselling sessions (n = 36), 14% in the self-help group and 25% in the counselling group dropped out without completing baseline questionnaires. For the 58 women who completed the baseline (n=31 in self help, n=27 in counselling group), the mean age of the sample was 53 years old (range 35-72) and average years since diagnosis was 3.5. These women were also well educated, with 21% indicating their ethnicity as being other than Caucasian. Topics covered in *Tendrils* program were similar to *GyneGals* and included: genital anatomy (including a unique interactive vulvar self-portrait with pain and pleasure mapping); causes and treatment options for loss of desire or orgasm problems; resuming “sex” (not defined) comfortably through sensate focus exercises; sexual issues related to ostomies or incontinence; dating; lesbian relationships; and various coping strategies. The three, in-person counselling supplemental sessions were guided by a therapist manual and facilitated by mental health

professionals who provided counselling, guided the women through the website, and discussed behavioural homework.

Results revealed that the women who received counselling had significant improvements in their sexual functioning (FSFI general scores only) compared to the self-help group. Changes in FSFI general scores in the counselled group remained significant at the 6-month follow-up, however FSFI scores did not surpass the clinical cut-off score (indicating ongoing difficulties) (Schover et al., 2013). A trend towards improvement was also observed in the self-help group (within group difference, $p = 0.054$), however, suggesting the intervention could also be beneficial even without the additional counselling. Significant improvements in sexual interest were observed in the counselled group compared to the self-help group at post-treatment, however these regressed at the 6-month follow-up. Sexual interest in the self-help group improved slightly over time. On nonsexual domains, significant improvements were observed in emotional distress (measured by the Brief Symptom Inventory-18 (BSI)) and overall quality of life (measured by the Quality of Life in Adult Cancer Survivors (QLACS)) for both groups across time, but these improvements remained significant only at post-treatment for the self-help group (Schover et al.). This is an interesting finding considering the only significant difference between the two groups was that the *counselled* group rated the intervention more positively on addressing their emotional concerns according to the program evaluations. The authors did not provide any explanation or theories that could account for this anomaly. It also remains unknown the extent to which partners were involved in this intervention or how it may have impacted the couple or their sexual relationship.

It is important to interpret these results with some level of caution due to the low uptake (approximately 10.4%) and high rates of attrition (56% from initial randomization to the 6 month

follow-up) that were observed during the course of this research. The only significant participant characteristic that was found to be associated with dropping out was age (women ≤ 49 were more likely to drop out) (Schover et al., 2013). Although 81% of those in the counselled group completed the counselling, there was a greater dropout rate among those in that group compared to the self-help group at each time point. The authors suggest that the burden of attending additional counselling appointments could account for the higher rate of attrition observed in the counselling group (Schover et al.). Again, quantitative interviewing would have been a useful addition to this study to better understand the participants' experiences of the two program delivery formats.

An interesting and helpful element that Schover et al. (2013) added to their research, was electronically recorded website usage (time spent) for each participant across the entire study period. During the 12-week intervention period, usage (in total minutes) was not significantly different between the groups (self-help, $M=108.6$ minutes; counselled, $M=143.4$ minutes) and was very similar between groups for the entire study trajectory (combined sample $M=149.0$ minutes). Interestingly, what was not discussed was what appears to be rather low rates of time spent engaged in the online intervention. The average time spent per week on each module among the whole sample averaged at approximately 15 minutes per week. This questions the level of engagement participants had with the online material. It is difficult to imagine how spending 15 minutes a week on *Tendrils* could adequately cover the information provided in the intervention or lead to lasting change. It would have been helpful to know more about how participants engaged with the program and how much time was spent on the suggested exercises that were not online.

Perhaps attaining the information presented in *Tendrils* was adequate enough to help

women with their sexual concerns (i.e., psychoeducation alone). A trend for usage time across the entire study period was found to be associated with improvement in sexual interest at 6-months post-intervention. However, the researchers found that the self-help group spent significantly more minutes on the website from post-treatment to the 6-month follow-up, which was consistent with the improvements seen in their sexual interest scores during that time (Schover et al., 2013). Observed improvements made in the counselling group by post-treatment declined from post-treatment to the 6-month follow-up as did the amount of time this group spent on the website between these time points. Since both groups rated *Tendrils* positively, these results could suggest that such online interventions used as self-help may be as effective as those that are facilitated by additional in-person counselling. On the other hand, these results could have depended on the quality of the in-person counselling, the low numbers of counselling sessions provided, or the extra time involved for participants in using both the online intervention plus attending counselling sessions – issues that qualitative interviews with participants may have shed further light on.

Taken together, the above studies indicate that online interventions aimed at improving sexual wellbeing after reproductive cancer treatments appear to be somewhat effective in helping cancer survivors improve their sexual wellbeing and relationships. The online format can provide a safe, confidential, and highly accessible space to acquire information on sexuality after cancer treatment. Although more research is needed, these studies provide evidence to suggest that online interventions are effective, with or without the further addition of professional support or counselling. Currently I am not aware of any online interventions targeting sexual difficulties for colorectal cancer survivors. The addition of qualitative interviews on participant experiences with such online interventions would provide very useful information about how participants

engage with online formats, including the benefits and challenges of using such a modality.

OPES: Online Psychoeducation for Sexual Health in Cancer Survivors Program

Considering the existing support for the efficacy of psychoeducational interventions that include skills-based training, aspects of sexual therapy and mindfulness along with the feasibility, efficacy, and advantages of offering such interventions in an online format, the Online Psychoeducation for Sexual Health in Cancer Survivors (OPES) was developed (Brotto et al., 2015).

Description of the OPES program. The Online Psychoeducation for Sexual Health in Cancer Survivors (OPES) program was an adaptation of Brotto and colleagues two aforementioned face-to-face PED interventions (Brotto et al., 2008; Brotto et al., 2012) that were modified to an online format. Another difference was that OPES was intended to be used largely as self-help, although a research assistant was available to provide support and trouble-shooting advice for those who were having difficulties navigating through the program. The OPES program modules incorporated: psychoeducation; cognitive-behavioural therapy; skills-based learning; sexual therapy; and mindfulness.

The OPES program consisted of 12 modules in an on-line format, with one new topic per week being delivered over the 12 weeks of the program (see Appendix B for a detailed description of the program and content of each of the 12 modules). Participants were required to complete each module in order, before advancing to the next module. Some modules (e.g., 1 and 2) involved reading and reflecting, whereas subsequent modules introduced material to be practiced (e.g., sensate focus) – some of these on a daily basis (e.g., mindfulness meditation). An online discussion board was also available where participants could post questions for the program facilitators or other participants.

The primary focus of the OPES program was to assist in decreasing sexually-related distress among female survivors of gynaecological cancers, and female and male survivors of colorectal cancers. The secondary aim of this intervention was to improve sexual functioning, mood, relationship satisfaction, and general quality of life.

OPES study procedures. Participants were recruited from the years 2010 to 2013 through the BC Cancer Agency, the Erie St. Clair Regional Cancer Program at Windsor Regional Hospital in Ontario, and the Memorial Sloan Kettering Cancer Center in New York. Inclusion criteria for the OPES study included *partnered* women and men from 19 to 70 years of age who had treatment for colorectal or gynaecological cancer in the previous five years. Participants in the study had to be at least 6 months post-surgery and not currently receiving any treatment (i.e., chemotherapy, radiation, or surgery). In order to be eligible, participants were required to be currently experiencing a sexual dysfunction or sexual difficulty that was distressing to them or was perceived as having a negative impact on their relationship. Whether individuals met these criteria was determined during a telephone-screening interview. Participants had to be fluent in English and have access to, and basic knowledge of, operating a computer. Given the prevalence of depressive symptoms in cancer patients (Sadovsky et al., 2010) and the increased risk for hospitalization for depression and suicide risk among cancer survivors (Dalton, Laursen, Ross, Mortensen, & Johansen, 2009), participants were screened for depression during the initial screening interview, using the National Mental Health Association's 10-item depression screen. Individuals who answered yes to 5 or more questions, or answered yes to having thoughts of suicide or death, were excluded from participation and given appropriate referral information. Severe depression has also been found to have a negative effect on sexual functioning and when depression is adequately treated, sexual complaints can dissipate (Fabre & Smith, 2012;

Hartmann, 2007; Zajecka et al., 2002).

A few exceptions were made to the inclusion criteria. A limited number of partnered individuals who received treatment for prostate ($n = 1$) and breast ($n = 3$) cancer discovered OPES through recruitment posters and requested permission to participate in the program out of personal interest, and because there was a lack of available psychological interventions addressing their sexual concerns. They were permitted to participate in the program with the understanding that some of the program material would be aimed at the issues faced by gynaecological and colorectal cancer survivors. It was not anticipated this would have a significant impact on this study as the vast majority of the OPES program is applicable to survivors of any cancer. In fact, a majority of the program is applicable to women who are experiencing problems with low sexual desire/arousal, regardless of whether or not they have had cancer (see Brotto, Basson, & Luria, 2008). Only one section in Module 1 addressed specific information for gynaecological and colorectal cancer survivors. Of note, all but one woman with breast cancer eventually withdrew from the program. An exception was also made for two women (one who had ovarian cancer and the other had colon cancer) who were not currently in a relationship but wanted to participate because they felt their sexual concerns were preventing them from starting a new intimate relationship. This was also not anticipated as being a significant problem as the majority of the OPES program involves individual activities that do not require a partner's involvement. The only partner specific aspects are in Module 7, which includes communication exercises, and in Module 8, which includes a partner sensate focus exercise. The woman who had ovarian cancer completed the study while the other dropped out.

Following receipt of each participant's signed consent form, the research assistant provided each participant with access to a password-protected website housing the confidential

psychological assessment measures and the treatment program materials. Given that participants were recruited at various times, participants were at different stages of the 12-week OPES program throughout the three year duration of the study. The OPES program's 12 modules and exercises varied in how much time was required to complete them. Participants were informed that, on average, each module would take approximately 60 minutes to complete, and would be administered once per week. Most participants progressed through the modules at a more self-directed pace, with many participants requesting and requiring more time than 60 minutes, and often a week or more, to complete some modules.

Quantitative indicators of OPES program. A total of 123 cancer survivors consented to participate in the OPES study. Of these, four dropped out before receiving their password to access to the online program. Another seven withdrew before completing the OPES baseline questionnaire. Of the remaining 112 participants, only 13 men and 36 women (43.75%) completed all twelve modules and the pre-, post- and 6 month follow-up assessments. However, an additional 12 participants (10 women and 2 men) provided complete pre- and post-intervention data despite only partially completing the full 12 modules of the OPES program. The minimum number of modules completed was 7 and the maximum was 11 (one participant dropped out during Module 7, six in Module 8, two each in Module 9 and 10, and one in Module 11). Analysis of demographic and outcome measures were based on this combined sample (n=61) of 46 females and 15 males. The average time since diagnosis was 4.6 years for men and 3.9 years for women. The mean age for female participants was 55.0 years (SD=9.58) and for male participants was 59.7 years (SD=6.77). The mean current relationship duration for the men was 26.9 years (SD=14.2) and for the women was 22.2 years (SD=14.2). The majority of participants identified as Euro Caucasian (93.5%). All aside from one participant identified as

being heterosexual. The participants were generally well-educated with 80% of the men and 82.6% of the women having completed college or trade school. Of the original 112 participants in the study, 42.9% were survivors of gynaecological cancer, 42.9% had survived colo/rectal cancer, and 3.2.% had other types of cancer (breast or prostate). Of the final 61 participants, 55.7% (n=34) had gynaecological cancer, 42.6% had colo/rectal (n=26), and 1.6% (n=1) had breast cancer. The participants took anywhere from 8 to 111 weeks (M=29.94 weeks, SD=19.40) to complete the OPES program, from the time they were provided with their username and password to access the program, to when they completed the 12th module (or the post-intervention questionnaire). Women were significantly more likely to complete all modules and assessments than men (48.6% versus 32.5%, $p=0.052$).

Compared to those who completed all the OPES modules and three assessments, those who dropped out rated their relationship connection, satisfaction, and cohesion as lower, and men indicated lower satisfaction with their erectile functioning. Reasons provided by participants for withdrawing from the study included: emotional distress over the topic, being too busy, feeling that the program did not meet their expectations, discomfort concerning the program material, perceiving that the program was not useful because their sexual difficulties were due to the physical impairments of surgery and not psychological (common among men), the online modality was too impersonal, loss of interest, and technical problems with the website. Some participants withdrew due to various life crises (e.g. death of a family member, caring for ailing parents, relationship challenges or termination, cancer recurrence, ongoing health challenges, etc.). One male participant passed away unrelated to cancer.

In order to investigate the OPES program's efficacy in decreasing the primary outcome of sexual distress, and the secondary outcomes of male and female sexual functioning, dyadic

adjustment and mood, the following outcome measures were used: the FSDS, FSFI, IIEF, DAS, and BDI. Each participant completed these measures before starting the OPES program, immediately after completing the program, and again 6 months later. In terms of the findings, significant interactions between treatment and gender were found on both sex-related distress and depressive symptoms ($p < .001$). Women reported more sexual distress and depressive symptoms immediately prior to starting the OPES modules, both of which significantly decreased at completion of the program. Somewhat surprisingly, the men started out with less sexual distress and depressive symptoms than the women, but had only a marginal increase in both, following completion of the program. No interaction between treatment and gender was found for changes in relationship adjustment following completion of the OPES treatment program. Curiously, while no changes were found from pre- to post- treatment in relationship satisfaction or cohesion, there was a *decrease* in relationship consensus for men and affection for both women and men who completed the program. This suggests that the OPES program, which targeted individuals but not their partners specifically, may have been missing important elements that could have improved aspects of relationship adjustment (Brotto et al., 2015).

With regards to women's sexual functioning as measured by the FSFI, there was a reported decrease in sexual pain, and significant improvements in sexual desire, sexual arousal, lubrication, orgasm, sexual satisfaction, and overall sexual function immediately following completion of the OPES program. The women's improvements in depressive symptoms, sexual distress, and sexual functioning were maintained six months after completing the OPES program.

Even though it is difficult to make any conclusive statements about the program's benefit for men given the small male sample size of those who provided both pre- and post-intervention data ($n=15$), the only significant improvement reported in the men's sexual functioning from pre-

to post was on intercourse satisfaction, with a trend towards increased sexual desire. No significant changes for men were evident in the areas of depression, sexual distress, or sexual functioning (IIEF subscale scores of erectile functioning, orgasm, overall satisfaction, and overall sexual functioning) at the six month post-OPES follow-up.

In sum, although the OPES program appeared to be helpful at the 6 month follow-up, in reducing women's sexual distress and depressive symptoms, OPES was not as effective for male participants. Because the male participants were colorectal cancer survivors and there is a dearth of psychological interventions targeting sexual difficulties for this population, it is difficult to know whether gender, or cancer type, or both, affected male participation rates in the OPES study and the effectiveness of the program for men. The OPES study also suffered from high drop out rates in general, especially for men, and overall low male participation rates. The overall attrition rate of 56.25% for women and men (who did not complete the full program) was particularly high, although comparable to other empirically studied psychological interventions for addressing sexual complaints among cancer survivors (Brotto et al., 2010; Schover et al., 2013). Finally, the OPES program took a much longer time to complete than the expected 12 weeks for the vast majority of participants. Considering it took participants on average of over 7 months to complete the program, this raises considerable questions concerning the format, content and online delivery of the OPES program along with the direct impact this program had on improving sexually related outcomes.

It would appear from these findings that the OPES program may be most helpful for a subset of reproductive and colorectal cancer survivors, and in particular, women. High drop out rates, excessive time to completion, and the apparent ineffectiveness of OPES for men in particular, provides rationale for conducting the current study. If psychoeducation interventions

like OPES are to be successful, it is important to learn, first of all, what motivated those who completed the program and to learn more about the specific challenges experienced by participants who completed the program. It is also prudent to gain some understanding of why it took participants significantly longer to complete the 12-week program than anticipated and expected. Another anticipated benefit of doing such research is that it could also increase our understanding of how participants define “success,” as the outcome measures used in research may not reflect what participants consider success in their sex lives.

Summary of Psychological/ Psychoeducational Intervention Research

Reviews of various interventions, mostly psychological, targeting sexual problems following cancer treatments have been discussed elsewhere (i.e., Bober & Varela, 2012; Brotto et al., 2010; Taylor et al., 2011; Varela, et al., 2013). A similar review of online interventions has not yet been published. In sum, these reviews addressed the difficulties in determining what interventions are most effective in helping improve sexual wellbeing after cancer treatment among survivors of reproductive and colorectal cancer survivors. Major limitations that were noted are due to the multiple methodological challenges when examining the intervention literature. First, the majority of studies have small sample sizes that impede statistical power and report high attrition rates (Brotto et al., 2010; Taylor et al., 2011), making it difficult to determine efficacy even when participants report that the intervention was beneficial. Second, the lack of control data in several intervention studies has been a major criticism (Bober & Varela, 2012, Brotto et al., 2010). Third, studies also vary on participant eligibility concerning their treatment trajectory – some interventions have recruited newly diagnosed patients before or soon after their treatment, while others have targeted cancer survivors several months to years after treatment completion. This suggests a lack of consensus on the best time to treat patient’s

sexual concerns (Taylor et al.). Fourth, there is a lack of consistency in screening for sexual difficulties or classifying problems pre-treatment, which Taylor et al. argue prevents effective delivery of targeted interventions. Finally, the majority of interventions are broad-based, do not address specific sexual problems (i.e., desire versus pain), and consist of a variety of components (i.e., education, skills-training, providing medical information, resources, individual versus group counselling, or peer support) making it hard to tease apart what aspects are helpful for what sexual problems (Taylor et al.). On the other hand, it is possible that individual interventions which approach sexuality from a wholistic and multidimensional framework, targeting the specific needs of specific participants, are essential in helping more patients improve their sexual wellbeing and quality of life after cancer (Bober & Varela, 2012; Brotto et al., 2010; Cleary & Hegarty; Gilbert, Ussher, & Perz, 2010).

Other critics in cancer-related sexuality research comment on the inadequacy of the available sexual outcome measures (Arrington, Cofrancesco, & Wu, 2004; Jeffrey et al., 2009). For example, a variety of sexual outcome measures have been used in the intervention research, many of which have not been validated for use in cancer populations, have methodological flaws, or approach sexual wellbeing from a reductionist or physiological framework focused on the sexual response cycle, intercourse and orgasm (Jeffrey et al.; Taylor et al., 2011). The vast majority fail to include important domains related to sexual wellbeing such as sexual attitudes, motivations, values, expectations, sexual self-esteem, sexual self-image, sexual roles, partner functioning or perceptions, and health-specific sexual challenges (Arrington et al.; Jeffrey et al.). All of these dimensions may be important for cancer survivors who may be struggling with a variety of quality of life challenges. Arrington et al. point out that considering the reliance we have on available measures of sexual functioning in determining sexual wellbeing, the

development of most instruments have failed to incorporate, or had limited patient input in their design. Rather, most have been based on clinical experience, literature review, and previous questionnaires and do not take into account patients' experiences. Without patient input, resources could be wasted in developing interventions that do not adequately meet patient needs or address what is important for them. Furthermore, a potential consequence of this omission is that what researchers determine as treatment "success" may not accurately reflect what participants perceive as success. As previously highlighted in this chapter, qualitative participant feedback can assist researchers in improving sexual outcome measures (i.e., Maughan & Clark, 2001; Jeffrey et al.).

Finally, this body of research has also received criticism for focusing predominantly on the relationship between treatments and their impact on a patient's "sexual functioning" (or genital function), with the resumption of sexual intercourse post-diagnosis, and achieving orgasm, as the hallmark of sexual health. These presuppositions have largely been made without taking into account patient perspectives considering qualitative data focusing on patient issues of intimacy and sexuality is rare (Hordern, 2008).

Despite these shortcomings in the intervention literature reviewed here, it is clear that psychoeducational interventions that reflect a bio-psycho-social conceptualization of sexual health can enhance the quality of life among reproductive and colorectal cancer survivors (and patients), and reduce sexual difficulties following cancer and its treatment. In order to continue to develop and improve upon these interventions, and target those populations who will benefit from these treatments, qualitative inquiries are likely to provide valuable information.

Conclusion

There is a growing body of qualitative research that has investigated the impact of reproductive and colorectal cancer treatment on the sexual lives of patients and survivors (i.e., Flynn et al., 2011; Fortune-Greeley et al., 2009; Tighe, Molassiotis, Morris, & Richardson, 2011; Ussher, Perz, Gilbert, Wong, & Hobbs, 2013), but to date, rarely has qualitative research been included in examining *how* patients and survivors experience psychological interventions for helping them with their sexual problems. This makes it difficult to fully understand how and in what ways these interventions have been found to be effective for participants

While some interventions have focused on a narrow aspect of sexual health (e.g., vaginal health or menopause), many have taken a more wholistic approach to sexual health by addressing multiple domains of sexuality (i.e., relationship, communication, body image, mood). Yet, the research fails to adequately inform us on how the bio-psycho-social aspects of participants' lives interact and impact their participation and success in an intervention. In addition, poor recruitment for these programs and high attrition rates imply these programs may not be perceived as helpful, or they may not be meeting the needs of a large number of people suffering with sexual problems after cancer. Therefore, empirical research that focuses solely on quantitative analyses is missing a wealth of rich, useful and important information about individuals' experiences and what they find (un)helpful in ameliorating their sexual difficulties after cancer. While there is moderate evidence for the effectiveness of psychoeducational interventions in treating sexual sequelae after reproductive and colorectal cancers (Brotto et al., 2010; Taylor et al., 2011; Varela & Bober, 2013), it is hard to determine what aspects of the aforementioned interventions work, for whom, and how these programs are experienced by those who participate in them.

This review highlights the need for, and importance of, inquiring into the lived experiences of reproductive and colorectal cancer survivors who have completed the on-line OPES psychoeducation intervention program, in terms of their experiences of the program and its perceived effectiveness in healing their sexual lives after cancer treatment. Acquiring a deeper understanding of participant experiences through qualitative inquiry will be of great value to health professionals on how we can improve our clinical support of cancer survivors.

Chapter 3: Methodology

The purpose of this study was to gain a more in-depth and comprehensive understanding of women's overall experiences of working through the Online Psychoeducational Program for Sexual Difficulties (OPES) aimed at healing the sexual aftermath following the diagnosis and treatment of reproductive or colorectal cancer. A narrative method of inquiry was used to address my research questions: ***“How do women experience the OPES online psychoeducational program for sexual difficulties after cancer treatment, and what changes did they experience in terms of their sexual life and relationship, during and following completion of the program”.***

Narrative research is a flourishing and ever-evolving type of qualitative inquiry and theoretical approach that revolves around an interest in life experiences as narrated by those who live them (Chase, 2011). It is an approach that privileges individuals' lived experiences (Marshall & Rossman, 2011). Although narrative researchers' interests, goals, theories and methodologies vary substantially, Chase (2011) defines narrative as: “as a distinct form of discourse: as meaning making through the shaping or ordering of experience, a way of understanding one's own or other's actions, of organizing events and objects into a meaningful whole, of connecting and seeing the consequences of actions and events over time” (p. 421). Rather than generating generalized descriptions or searching for central tendencies, narrative interviewing involves “the generation of detailed ‘stories’ of experience” (Riessman, 2006a, p.3) through which an individual's subjective reality can be captured.

Using a narrative inquiry approach to answer my research question is a novel and potentially illuminating method of exploring cancer survivors' experiences of working through and completing the OPES treatment program. Narrative inquiry is the most appropriate

methodology for my research question because it has the power to capture individuals' subjective realities (i.e., Riessman, 2003). Narrative research, rooted in interpretive hermeneutics and phenomenology (Josselson, 2006), provides a window into how individuals perceive, organize, give meaning to, and express their understandings of themselves, their experiences, and their worlds (Mishler, 1986). This is an exciting alternative approach to studying human sexuality. Rather than relying solely on a constrictive model of sexual health espoused from a medical/ physiological perspective, or using the more common question-answer style interviewing technique, a narrative approach will help to explicate what sexual wellbeing in the aftermath of cancer means to the women in this study.

Stephens and Breheny (2013) explain that, by using a more systematic approach to the stories participants tell and interpreting the meaning in their narratives, we can also begin to notice how identity and experience are constructed at the intersection of personal, interpersonal, and cultural narratives – making this a valuable methodology for researching the multidimensional construct of sexual wellbeing after cancer and the experiences of those who completed the OPES treatment program (Cleary & Hegarty, 2011; Gilbert, Ussher, & Perz, 2010, 2011). It is also my hope that, through a narrative analysis, the findings from this narrative research study, may add some valuable and important insights in explaining the high drop out rates, the long time to completion, and quantitative findings in the initial OPES study. Finally, a narrative research methodology is also well-suited to my training as a counsellor. Narrative inquiry is complementary to counselling as it privileges conversations and relationships, and therefore is applicable to clinical practice (Riessman & Speedy, 2007), adding to the pragmatic value of this research.

Situating Myself, the Researcher

Narrative inquiry is a collaborative endeavor (Mishler, 1986; Reissman, 1993, 2003; Stephens & Breheny 2013) where interpretation is co-constructed at every level from the interview to transcription to analysis (Arvay, 2003; Mishler, 1986; Reissman, 1993, 2003, 2006a; Riessman & Speedy, 2007). According to philosophical hermeneutics, the “interpreter [researcher] encounters a text from within his or her *prejudices*; interpretation is like a conversational dialogue through which meaning is a product of interaction” (Polkinghorne, 2007, p. 483). As interpretive hermeneutics informs this research inquiry, I believe it is impossible for me to transcend my own historical, cultural, and personal context/ circumstances and this will come to influence how I hear, read, understand and interpret participants’ narratives. This is why it is important for me to situate myself as a co-constructor and collaborator in the process of narrative analysis (Mishler, 1986). I begin by indicating my presuppositions in order to increase my own transparency and to help me set aside any expectations I may have so that my participants’ stories and their own meanings can take precedence in the interviews and emerge in my analyses.

On the one hand, I am not a cancer survivor, so while I can imagine ways in which receiving a cancer diagnosis and experiencing negative sexual sequelae following treatment may affect me, my sexual life and intimate relationship, I am far removed from the reality of having cancer compared to those from whom I wished to learn from in this study. On the other hand, I have worked as a student researcher/ assistant in the field of oncology since 2008 through the UBC Sexual Health Laboratory (under the supervision of Dr. Lori Brotto) and, for a couple years, at the Vancouver Prostate Centre (under the supervision of Dr. Joyce Davison). During this time, I have connected with many survivors of gynaecological or prostate cancer through

various research investigations and have come to appreciate the impact that a cancer diagnosis and treatment can have on people's intimate lives, including the various ways in which people cope. I have listened to people speak of some of the challenges they have experienced with hampered sexual wellbeing, relationship stress, and emotional distress. As these stories seem to have predominated my experiences in this work, I had to be mindful of giving these aspects of participants stories more attention at the cost of attending to aspects of strength and resilience in their stories of the sexual aftermath of cancer. However, in my previous work I also heard from those who reported no sexual problems or others who actually experienced an increase in sexual activity and relationship intimacy in the aftermath of cancer.

Together, I have been touched and humbled by how people have shared with me such very personal stories of both their pain and survival. Often people have thanked me for listening to their stories and validating their experiences from which I derive a lot of value. Importantly, these moments have been the closest I have personally come to cancer. I had a grandfather who died from pancreatic cancer when I was quite young (and left mostly in the dark about it), a grandmother who recently passed away in her late 80s from lung cancer (due to smoking), and an aunt in her 60s who also recently succumbed very quickly to lung cancer (not a smoker), and have a close family friend (in his 70s) who is battling bladder cancer. So in my personal experience, cancer happened to only a few loved ones in the later years of their lives and no one ever spoken about how cancer has impacted his or her sexual or intimate lives! It seemed as if "sex" was a non-issue compared to survival or coming to the end of ones life. Perhaps having been influenced by my father (a bit of a cynic) who was a family doctor for years and who appeared to be from the generation of doctors who were more concerned with quality of life than survival rates, I have been curious, interested, and concerned in knowing more about people's

lived experiences in the aftermath of medical interventions. I think this has had a positive influence in my role as a researcher in this area.

Something that has especially stood out for me in conducting quantitative research is the failure of commonly used and validated measures (i.e., the FSFI and the IIEF) to capture the complexity, depth, and multidimensional realities of people's experiences, understanding, and discussions about their sexual lives. When completing study measurements such as the FSFI, for example, it was not uncommon for me to observe (or receive feedback about) how participants struggled with simplistic reductions of their sexual lives into the limited domains of desire, arousal, intercourse, and orgasm without taking into consideration the context within which they experience their sexuality. Not uncommonly, people asked how they should respond to such and such a question in the context of certain life or relationship circumstances (which they would share with me) or felt a need to explain to me the reasons *why* they responded to questions in the way they did. It always struck me how their stories had very important and valuable information that quantitative researchers' validated sexual measures fail to reveal. This is one significant reason why I chose to pursue a narrative inquiry in this research study.

My understanding of sexuality, not unlike my participants, has been heavily influenced by the socio-cultural (and medical) discourses of what is normal, or healthy sex in our society: based on desire, arousal (i.e., erections for men and lubrication for women), penile-vaginal intercourse (the coital imperative), and orgasm. It has been reinforced by the common discourses in the medical community and throughout research on cancer and sexual functioning that focuses heavily on the genitals. However, I have been introduced more recently to the arguments set forward by feminist scholars and social constructivists who argue for the importance of a more holistic approach to understanding sexuality and intimacy after cancer (i.e., Hordern, 2008;

Ussher, Perz, Gilbert, Wong, & Hobbs, 2013). This paradigm conflicts with how I have come to understand sexuality that was more in line with popular societal discourses. More importantly, it has created a new awareness of how such a reductionist view of sexual intimacy can limit the possibilities for cancer survivors in discovering new satisfying and pleasurable ways of having a sexually and intimately invigorating life in the aftermath of cancer. The social-constructivist approach to understanding human sexuality and intimacy is not only something I find exciting, but also it opens up many more avenues for expanding how we define, understand, and experience sexuality in our lives with or without cancer! In sum, I appreciated that my own understanding of a more wholistic perspective of sexuality from a social constructivist viewpoint could impact how I heard my participants and interpreted their stories. While there are advantages to this standpoint such as being more open to hearing and understanding a variety of ways in which participants may conceptualize their sexual experiences, self-perceptions and relationships before and after cancer, I was mindful that my participants may understand their own sexual lives from a more conventional (genital and intercourse oriented) sexual perspective.

The knowledge gained from my previous experience as a research assistant and having supported OPES participants through the program, I had some expectations about what I may find in my research. Because participants in this study completed the OPES program, I expected their experiences with the OPES program may be quite different from those who could not or chose not to finish the program. I expected my participants would likely talk about having healthy and supportive relationships with their spouses which would have encouraged them to complete the OPES program. I also expected my participants were highly motivated and prioritized improving their sexual lives and relationship. While I expected my participants would have found the program helpful and beneficial in improving their level of knowledge, mood,

relationship intimacy, and sexual functioning, I also anticipated learning that they faced and overcame a variety of challenges such as: program fatigue (12 modules being a lengthy commitment), low homework compliance, and managing competing life demands and responsibilities, and perhaps unrealistic expectations of returning to a sexual life similar to that before cancer.

Throughout the process of interviewing participants, transcribing, and analyzing data, I undertook a process of reflexivity through self-reflection and informal journal writing in order to reflect on how my own beliefs, values, and conceptions may influence my understanding of participants' experiences and how I may be influenced by my participants in this narrative inquiry (Finlay & Gough, 2003). My journaling involved writing a stream of consciousness that helped inform how I interpreted my data. I also made notations in the margins of my transcripts (e.g., my initial reactions, personal thoughts and/or feelings; reading "in-between the lines") that helped illuminate some of my personal biases and highlighted where I needed to explore my data from a different perspective or seek further consultation from my supervisor.

Research Procedures

Participant criteria and recruitment. An amendment to the original study protocol was approved by the UBC Research Ethics Board to conduct this study. There were a number of criteria involved in the selection of participants for this study, and therefore this was a purposive sample. In order to investigate my research questions, the participants were selected from a subsample of participants who: (1) originally met the eligibility criteria of the OPES study (having completed treatment for gynaecological or colorectal cancer, including women who had been treated for breast cancer and were permitted to enrol in the program); (2) consented to participate in the OPES program; and (3) who completed the 12 modules of the OPES study

program as well as the pre-, post- and 6-month follow-up questionnaires. Only those participants residing in British Columbia with whom I had contact with during my involvement with the OPES program as a RA were considered for participation in consideration of both the benefit of having face-to-face interviews in narrative research, and also due to the longer length of time it had been since other participants had completed the OPES program with previous RAs. This resulted in a potential sample of 21 OPES participants, 16 of whom I enrolled and followed to completion of the program (only one was male). In consideration of geographical, time, and financial constraints, the potential sample base was further limited to those individuals in BC who resided within a days travel from Vancouver. An initial 9 women were sent invitation emails (see Appendix C) to participate in an in-depth interview lasting approximately 90 minutes and a subsequent half hour validation interview after the initial analysis was completed. Of the 9 women approached, six agreed to participate (2 declined and one was interested but unavailable). Face-to-face interviews were scheduled at a private location and time convenient for each participant. Each participant was emailed a copy of the Informed Consent form (see Appendix D) for her perusal and review prior to our research interview.

Discussing one's sexual health and intimacy after cancer treatment can understandably be difficult and has the potential to cause discomfort or embarrassment for some participants, even when fully informed about the nature of the research and agree to participate. In order to help prevent any undue discomfort or harm to participants, it is not an uncommon practice in qualitative research to send participants the questions that will be asked before the interview (Langdrige, 2007). Therefore, one to two weeks prior to our scheduled interview, the researcher's orienting statement for the interview (see Appendix E) was sent to participants so as to inform them of my interview questions, and allow them some time to reflect on their

experiences of the OPES program before the interview.

I found I needed 6 participants to reach saturation (no new information arising from the interviews) in their narratives. The rationale of using such a small sample is that there is no generalizability in narrative research (Josselson, 2011) and this sample size is commonly found in Master's level qualitative research.

Data collection interviews. The use of in-depth, unstructured interviewing is essential in qualitative research, especially in eliciting people's experiences and meaning making (Brinkmann & Kvale, 2014; Kvale, 1996; Mishler, 1986; Riessman 2006a; Riessman; 2008; Rubin & Rubin, 2005). Kvale describes the richness of qualitative interviewing as creating a *construction site of knowledge*, "the qualitative research interview attempts to understand the world from the subjects' points of view, to unfold the meaning of peoples' experiences, to uncover their lived world prior to scientific explanations" (pp. 1). In order to answer my research questions, I conducted two interviews with each participant. The first interview was a largely unstructured, audio-taped interview focused on eliciting an in-depth and detailed story of her experiences of working through and completing the OPES program. These interviews lasted anywhere from approximately 90 minutes to 3 hours. The second interview, lasting from approximately 30 minutes to an hour, was conducted for the purpose of ensuring the trustworthiness of my data analysis.

Before each interview began, I reviewed the purpose of the study and informed consent with each participant. Limits of confidentiality were explained. As part of the informed consent process, each participant was reminded the interview would be audio-recorded, and recording only proceeded with her expressed agreement. Participants were also reminded that they were free to terminate the interview at any time, choose not to respond to any of my questions, or

refrain from sharing any intimate details they were not comfortable sharing with me. I also addressed any outstanding concerns or final questions a participant had, prior to proceeding with the interview or the signing of the consent form. Participants were then asked to sign two copies of the informed consent, one of which was provided to them to retain for their own records. The digital recorder was then turned on to begin audio-recording the interview.

Because it was my intention to work towards transforming the interviewee-interviewer relationship into one of narrator and listener (Chase, 2011), I emphasized to my participants that our interview was *not* going to be structured like a typical question-answer period, but rather my hope was that a relaxed conversational style would be able to unfold during the narrative interview. Consistent with Riessman (1993) and Chase's (2011) recommendations, I was conscious not to control the research interview and instead approached it as I would any other important conversation. To help facilitate a safe and comfortable atmosphere, I used my counselling skills of empathic listening, being attentive and engaged in what my participant had to share. Through eye contact and receptive body language, I demonstrated my genuine interest, care, warmth and openness, using minimal encouragers, matching tone, gestures and silences, and being mindful not to interrupt (Brinkmann & Kvale, 2014). These are skills that have long been important to me, both personally and professionally, but those I have also developed further in my counselling training over the past three years.

I began each interview by reading aloud to the participant my Research Orienting Statement (see Appendix E). The purpose of reading this statement was to establish a context for the interview and to encourage the participant to talk freely and openly about her experiences, and the meanings the participant derives from her experiences, with minimal interference from me (Brinkmann & Kvale, 2014). This was intended to help prevent me from introducing any

unintentional agenda items or bias that may deter the interviewee from her narrative and so I was also cognisant to follow her where she wanted or needed to go in her narrative (Mishler, 1986; Riessman, 1993). The series of open-ended probing questions, such as “How was that piece of information significant for you?” were used only as necessary to facilitate deepening a participant’s exploration of her experiences, clarify my understanding, or elucidate further detail if the interviewee’s story appears to lack personal meaning or understanding (Riessman, 1993). In line with the recommended aim of empowering interviewees (Mishler, 1986), this approach was intended to help foster a sense of safety and control over what each participant felt comfortable sharing about her personal experiences of such a sensitive and private topic as her sexuality and intimate relationships. When each participant’s story appeared to have reached its conclusion, and she confirmed she has nothing more to add, I turned off the recording device and we debriefed the interview (see Appendix F).

Data transcription and analysis. Interviews were transcribed verbatim to written text. While there is no standard set of procedures for narrative researchers to follow compared to other forms of qualitative analysis (Riessman, 1993), the importance of the transcription process in narrative inquiry is critical. Many scholars argue that data analysis begins with, and is not separate from, transcription (Lapadat & Lindsay, 1999; Riessman, 1993; Mishler, 1986). I followed Riessman’s (1993, 2008) suggested format for transcribing my interviews into a written text because of the freedom it permits to be innovative with one’s analysis. Riessman (1993, 2008) describes transcribing as a process involving *selection* and *reduction*. First, I began with a transcription of the entire interview, including any striking features of the conversation such as long pauses, emotional expression (i.e., laughing, crying, sighing, whispering, asides, false starts). It was my intention to make a conscious effort to pay attention to the content, and also to

any understandings that came from building the transcript through listening and re-listening to the recording (Lapadat & Lindsay, 1999). I then scrutinized the drafts of the transcripts by reading and rereading across all of the participants' transcribed interviews, highlighting and taking note of the common aspects of participating in the OPES program that emerged in each woman's story (e.g., participants' motivations, challenges, successes). These were then used to help organize each woman's narrative summary into various segments specifically related to her experiences with the OPES program. I then identified sections of the text that appeared to take the form of "narrative segments" – those parts of the conversation (i.e., other than questions and answers, pleasantries or arguments, chronicles, etc.) that took the form of a story or captured a seemingly poignant experience that was related to her having had cancer, its treatment, side-effects of treatment, her sexuality and sexual/ intimate relationship, and the OPES program. Narrative inquiry privileges the *voice within* each narrative rather than locating distinct themes or details across interviews (Riessman, 2008, p.12 as cited in Chase, 2011; also see Josselson 2007; Stephens & Breheny, 2013). In following Riessman's (1993; 2006b) suggestions, the process of analysing my narrative data required me to examine beyond the content in the narratives, and to set aside any preconceived notions or agenda to seek out evidence for any particular theory. There are no specific directions or orthodoxy on how to conduct narrative research (Josselson, 2011), however I attempted to follow Riessman's (2008) suggestions by incorporating two levels of data analysis in my transformation of each transcript into a "co-constructed" narrative summary of each woman's experience with the OPES program – a thematic analysis and a structural analysis. In my understanding of this research method in interpreting my participants' narratives, these were not necessarily two distinct methods of inquiry, but rather two layers of analysis that overlapped with and complimented each other. A thematic analysis was conducted

for each individual narrative where the emphasis was placed on the context of the transcribed text – *what* is said rather than how it is said, resulting in several emerging themes and subthemes within each narrative account. These themes and subthemes were subsumed under the various aspects of these participants’ participation in the OPES program. The *structural analysis* of each narrative placed emphasis on *how* a story was told or the *way* it was told, (i.e., how a narrative was organized; why did an interviewee develop her tale *this* way in conversation with *this* listener) (Riessman, 2008). Results of these analyses were then compared across all participants’ narrative summaries. This was helpful in finding what themes were similar or unique between the participants and across the stories they told (Riessman, 2006b). Although this strategy privileges the teller’s experience, interpretation is unavoidable as narratives are not only situated in the unique interaction between interviewee and interviewer, but also in the “social, cultural, and institutional discourse which must be brought to bear interpret them” (Riessman, 1993, p. 61).

Member checks. Following the completion of each narrative data analyses, a second interview was conducted with each participant to review and ensure that the “co-constructed” narrative that emerged from my analyses was an accurate reflection of each participant’s experiences (Riessman, 1993; Lincoln & Guba, 1985). The rationale for conducting these member checks was twofold: to support the trustworthiness of the research findings; and, to meet the standards of ethical practice in narrative research. It has been argued that the trustworthiness of qualitative research findings is inseparable from ethical principles of working collaboratively with people in this type of research endeavour (Marshall & Rossman, 2011). Riessman (1993) argues that it is important that we find out what participants think of our work, and their responses can often be a source of further insight into our analyses. Lincoln and Guba (1985)

also emphasize that credibility and trustworthiness of qualitative findings are increased when participants can affirm the researcher's interpretations/ representations of their lived experiences.

These "member checks," or validation interviews, were conducted either in-person, or over Facetime or Skype and lasted between 30 minutes and an hour. Two weeks prior to the validation interview, participants were provided with a copy of their personal narrative summaries to review at their leisure. With participants' consent, each participant's narrative was sent via email as an attached, encrypted and password protected PDF file. Passwords were provided separately, sent directly to the participant via text messaging to their personal cellular phones. One woman declined participating in validation interview because she was preoccupied with supporting her partner who was in ill health at the time. Of note, she also shared that she was experiencing participation fatigue with her involvement in the various aspects of the OPES program research which had stretched over a couple years. She was provided with her narrative summary for her own interest and was not obligated to complete the validation interview.

In each validation interview, a set of questions were asked in order to ensure that each woman's narrative summary was coherent, comprehensive, and an accurate representation of their experiences (Appendix G). These interviews also offered a final opportunity for participants to share any new insights regarding the benefits or challenges they experienced in participating in this study. Their feedback was taken into consideration in the analysis and refinement of the findings.

Trustworthiness of Findings

Conducting member checks is merely one aspect of strengthening our confidence in the trustworthiness of narrative analysis. Riessman (1993) echoes Mishler's (1986) argument that "traditional notions of reliability simply do not apply to narrative studies and validity must be

radically conceptualized” (p. 65). Polkinghorne (2007) explains that support for the trustworthiness of narrative research findings is an argumentative practice intended to “convince readers of the likelihood that the support for any claim is strong enough that the claim can serve as a basis for understanding of and action in the human realm” (p. 476). He further asserts that confidence in narrative inquiry claims can be strengthened when a researcher attends to threats to the trustworthiness (or rigor) of the findings. He defines these threats in the context of narrative research as:

“The disjunction between a person’s actual experienced meaning and his or her storied description has four sources: (a) the limits of language to capture the complexity and depth of experienced meaning; (b) the limits of reflection to bring notice to the layers of meaning that are present outside of awareness; (c) the resistance of people because of social desirability to reveal fully the entire complexities of the felt meanings of which they are aware; and (d) the complexity caused by the fact that texts are often a co-creation of the interviewer and participant (pp. 481).

To strengthen the rigor for my narrative inquiry, I addressed Polkinghorne’s (2007) suggestions by including the following four criteria in my research: resonance, comprehensiveness, coherence, and pragmatic value. These criteria are considered to be the gold standards for increasing rigor in narrative research (Kvale, 1996; Lieblich, Tuval-Mashiach, R., & Zilber, 1998; Riessman, 1993). *Coherence* (i.e., are the research findings understandable, do the narrative analyses/ co-constructed stories create a meaningful picture) was assessed through the member checks, and a comparison of these research findings with previous research and theories in the literature. *Comprehensiveness* (i.e., were the narratives rich with detailed description) was facilitated through: researcher journaling; facilitating an open and curious

interview style where participants were encouraged to explore what their experiences meant to them; liberally incorporating participants words and sentences throughout each narrative; member checks; and, receiving supervision throughout the research process. *Resonance* (i.e., does my co-constructed narrative summary resonate with each participant's experience of participating in the OPES program, and does it reflect their own understanding of their experiences) was addressed again through the member checks. *Pragmatic value* (i.e., was participating in this study a beneficial endeavour for participants, how can this research be helpful for the communities of researchers, clinicians, and patients) was achieved through member checks and by my transparency in the research methodology, including maintaining detailed records of how my interpretations were produced, and having primary data available to the members of my supervisory committee (Reissman, 1993; Terrett, 2011).

Ethical Considerations

While ethical considerations are of utmost importance to all researchers in counselling psychology, it has been very important for me to be cognizant of ethical issues that are pertinent to my research question and methodology. Sexual intimacy and cancer are both very private and sensitive topics that have the potential to bring up a variety of strong emotions for participants. In addition, because narrative research involves acquiring and reflecting on other people's lived experiences, every aspect of this research is touched by the ethics of the research relationship (Josselson, 2007). Although ethical practices in this narrative research have been discussed intermittently throughout this chapter, I want to briefly address a couple of remaining points.

Confidentiality and anonymity are of particular importance for my study participants and this was maintained throughout and after the research process. As already noted, audio files, transcripts (with identifying information removed), and participant information have been

password protected and saved on a secure computer database at the UBC Department of Obstetrics and Gynaecology. Audio-files will be deleted once the defence of this research has been complete while written documents will be saved for up to five years, at which time they will be destroyed. Signed consent forms will be stored in separate folders in a securely locked cabinet also in the Department of Obstetrics and Gynaecology, where I was the RA for the OPES study. Furthermore, member checks provided participants an opportunity to have any parts of their story that were not comfortable sharing, deleted from their narrative.

Given the prevalence of negative sexual sequelae of cancer and its treatment, it was important for me to be clear of my role as researcher rather than counsellor at the beginning of the research process (Haverkamp, 2005; Knox & Burkard, 2009; Seidman, 1991). I provided participants with a list of relevant referral resources for mental health professionals if the interview process caused them discomfort or distress, or if any one felt this was something she was interested in pursuing further (Appendix H).

Limitations

Due to the very personal and private nature of this investigation of sexual difficulties or sexual wellbeing within the context of cancer survivorship, these research findings are limited due to a variety of factors. The personal experiences these women had with completing the OPES program and the meaning it had for their sexual lives and relationships, were expressed only to the degree that they were willing and able to articulate their experiences. It was possible that the extent and depth of self-disclosure could have been influenced by feelings such as shame, awkwardness, embarrassment and/or apprehension around discussing the intimate details of their sexual lives and sexual self-perceptions, although this was not overly apparent in the interviews conducted with these women. However, such feelings are not uncommon in our

society that generally considers the public discourse of sexuality among strangers as taboo and arguably is rarely discussed even in many people's close relationships with friends, family, and romantic relationships, let alone with a researcher. Still, the beauty of this narrative inquiry was that it provides these women with an opportunity to discuss the sensitive topic of sexuality with a "neutral," empathic, understanding, and non-judgemental professional who has had previous experience in discussing sexuality and sexual concerns with a wide variety of participants in other research projects. In addition, those women who were recruited for this study and who were comfortable participating in this research may not be representative of the population in general nor of other OPES participants.

Another limitation is that, due to the participant pool from which this sample was recruited, this study included only those women who are in a heterosexual relationship. Consequently, the results of this study may not reflect the needs of unpartnered women, or Lesbian, Gay, Bisexual, Trans, and Queer (LGBTQ) cancer survivors. This is a major limitation of this study. There is evidence that unpartnered men and women suffering from loss of sexual functioning avoid pursuing intimate relationships after cancer treatment due to such things as embarrassment or lowered sexual confidence (i.e., Bober & Varela, 2012; Flynn et al., 2011) and research with the LGBTQ is severely lacking.

The current study was also limited by my lack of experience as a qualitative researcher in terms of narrative interviewing and systematically analysing textual data from transcribed interviews. This was addressed to the best of my ability through maintaining transparency in how I interpreted participant's stories, and by seeking supervision and feedback from my thesis supervisor, Dr. Judith Daniluk, who has substantial experience in qualitative research.

Chapter 4: Results

Overview of Findings

In this study I interviewed six female participants who were treated for gynaecological (n=3), colorectal (n=2) or breast cancer (n=1) and who completed the 12 OPES program modules as well as the pre-, post-, and 6-month follow-up questionnaires between 2011 and 2013. The time between their having completed the program modules to the time of our interview ranged from 14 months to 3 years. Women were aged between 46 and 71 at the time of their interview. All but one participant, were retired when they participated in the OPES program and all were in long-term, committed relationships ranging from 7 to 40 years. All participants provided, or were provided with, a pseudonym.

Each interview was transcribed verbatim and individual summaries of each woman's narrative were constructed. Six rich narratives were generated of the women's experiences of the OPES program, and the changes realized in their sexual lives and relationships during and following completion of the OPES program. These co-constructed narratives revealed both heterogeneity as well as significant homogeneity in how the women experienced the OPES program, including the challenges they faced and what helped motivate them to complete the program. The OPES program was one sometimes small but not necessarily insignificant, aspect of each woman's multifaceted journey towards her physical, psychological, relational, and sexual healing after cancer.

Each participant's background and cancer experience shaped how they experienced the OPES program and was included in each narrative summary as a means of providing further context to understanding each woman's experiences and perceptions on a deeper level. To a greater or lesser extent, each narrative addressed the following five aspects of completing the

OPES program: (a) motivations to complete the program; (b) challenges faced when engaged in the program; (c) perceived benefits experienced from participating in and completing the OPES program; (d) current sexual wellbeing after having participated in the program; and (e) feedback on how the OPES program may have better met their needs during their participation. It was my intention to organize each woman's narrative according to these categories in order to more clearly elucidate their experiences with the OPES program.

Another outcome of this narrative analysis was the identification of numerous common overlapping themes, and relevant subthemes, that represent my interpretation of the shared experiences among these six women who completed the OPES program. This chapter will include each co-constructed narrative with the main themes and subthemes of each woman's story included in italics. A summary table of the common themes and subthemes of the six narratives will follow as well as a brief discussion of important differences found among these narratives.

Participants' Co-constructed Narratives

Terry's narrative. Terry is a teacher in her mid-forties, married to a loving and supportive husband (second marriage), and a mother to two young teenagers from her previous marriage. They live in a small community in British Columbia. When she was in her late 30s, approximately 3 years after meeting her current husband, Terry was diagnosed with an aggressive form of breast cancer (HER2 positive) for which she received chemotherapy and surgery that covered about a three-year span, and an additional year of psychological counselling. Just under a year after completing breast cancer treatments, her doctors discovered abnormal (pre-cancerous) cysts growing on her ovaries during an appendectomy. Three months later, Terry's ovaries were surgically removed which put her into immediate menopause. Terry

started the OPES program approximately 18 months after her surgery. It took approximately 25 weeks for her to complete the OPES program. Approximately 14 months after finishing the program modules, she was interviewed for this study.

Relevant background information. Terry said from the outset, “I was a very sexual being before cancer.” She explained before cancer, sex was her main source of relaxation. It was a place where she could enjoy her body and escape from her mental busyness - her sole “calming outlet.” Sex also helped her feel connected to various parts of herself, like her thoughts, feelings, and physical body. With her second marriage, sex took on a new and important meaning – for the first time, sex became a place of deep intimate connection: “We had this amazing relationship, which was very playful and I mean, sex, sexual intercourse *was* intimate cause it was... there was just a closeness there that we, *I* hadn’t ever had before in my life.”

Terry recalled that while breast cancer did not have a serious impact on her sexual wellbeing, the threat of ovarian cancer, and the resulting surgery, was “a turning point in terms of everything, sexual and intimate. It just shifted, it reversed.” She recounted:

Suddenly I went from having sex drive, I mean, not as much after breast cancer, but certainly enough to form a healthy relationship, to having none. And not only to having none, but not even to have the physical ability to have sexual intercourse without lubrication.

The culmination of her breast cancer, years of treatment, and now ovarian cancer left her, she said, “feeling sooooo violated.” She recalled, “I was bruised emotionally and physically... I just shut down! I was just like, ‘Don’t touch me! Don’t come near me!’” On top of these changes, Terry also grappled with the idea, “so my body is just a cancer-making machine!” and “this is how I am going to die.”

Terry felt like she had nothing left and this infiltrated her relationship with her husband. The physical intimacy she and her husband had once shared, and the comfort it had offered her, now became a source of suffering. She recalled, “when he would come towards me for a hug... I would almost feel suffocated.” She explained that she became “closed off” and that it was really hard for her husband because “we had been so connected and so close.” As a result, Terry said, “We literally went back to almost, re-learning every single thing to do with intimacy,” because she had become “so terrified of everything.” Terry described some “coping mechanisms” that she and her husband had discovered – ways in which he could “come back into my personal space” (e.g., coming from behind to give her a hug). She spoke of these as “positive movements forward,” reminding her she still valued the physical part of her relationship. When she received the invitation letter to participate in the OPES study, Terry thought, “this will force me to focus... to put a priority on this part of my life, this intimacy part and a sexual part that has been nonexistent for a while and that I need to get back into being a part of.” She thought it would be good for her, offering her a “concrete set of steps” that she and her husband “could go through to get back to that place” that they valued.

Challenges faced when engaging in the OPES program. Several challenges arose for Terry in the process of completing the program, many of which continued to be difficult for her afterwards. *Psychological difficulties*, resulting from the dramatic drop she experienced in her sexual desire and physiological arousal (i.e., lubrication) following ovarian surgery, plagued her participation. This included *grief over the loss of her sexual self and relationship*, *emotional disruptions*, *relentless “mental noise,”* and often feeling *trapped in a vicious cycle*. Although her husband was extremely supportive, certain *relationship dynamics* impeded their moving forward sexually. Her experience of the OPES program *feeling like work* was a consistent theme

throughout her story which, according to her recollection, was further exacerbated by her *being quite fatigued* during that time. Because the program felt like *work, technical difficulties, program time constraints* and her *ambivalence with some program content* (i.e., module on erotic aids) served as *further barriers* she found she had to *work through*.

The first struggle she discussed when working through the OPES program was coming to the *realization that, sexually, things were never going to be the same*. Terry noticed such a dramatic change in her sexual response after her last surgery that when she and her husband first tried to be sexually intimate again, it felt to her like “*it was so false*” and “*forced;*” “*it just didn't seem natural.*” Terry said this made her feel very *angry and frustrated* because after “all the trauma” she had been through with cancer, she could not stand having “*something else... to work at!*” Her *anger and frustration*, she said, *shut her down* even more. She agreed she continues to be stuck in “that kind of *anger, grief phase.*” In her words:

I think one of the struggles through the program, was, that as I went through I also started to *realize that I can never go back*. It, it never will be the same. And it was a really, and still is, a very challenging truth to accept. Because I was so content, where I was... we had the perfect sexual relationship.

She recalled that the OPES exercises that involved her touching her own genitals were quite challenging because she said she *couldn't stop the noise in her head*: “Why am I having to do this? *Why is this so much work?* And why is it so painful?... I can't believe I'm here!” Terry pondered whether her difficulty was because she just wasn't emotionally “there yet” at the time.

Modules that included exercises that involved being touched by her husband were especially difficult because these would trigger *panic attacks* – something that started after her ovarian cancer diagnosis. In Terry's words:

I'm still trying to work with that, trying to... to physically, talk, myself through, 'this is not a threat... This is just me being freaked out because of everything that's happened...I have to concentrate that this man here is okay, and everything's fine.

Understandably, she admitted that this *self-talk* she used/ uses to calm herself is “*not very conducive to sexual intimacy*.” She also felt strong feelings of *guilt* about thinking: “*I don't really want to do this...I'm doing this for you, I'm not doing this for me*,” which she said was the biggest and hardest part of the process. Considering herself a “people-pleaser,” Terry further explained she also felt *guilt* about her husband not getting his sexual needs met. During those few times he convinced her to try and allow him to give her pleasure (while she concentrated on “trying to relax”), she recalled thinking, “*Well I should be doing something back... I can't, I can't just take, I have to give*.” This further sabotaged her ability to be in the moment and feel okay with his touch.

Terry discussed her process of being caught up in this “*catch-22*.” Despite the fact that a strong part of her did not want to engage in sexual activity with her husband, another equally strong part longed to return to that intimacy she once shared with her him. She shared her *confusion*: “but this man loves me and he adores me and I want to be part of this... my whole life, this is what I worked towards! I don't want to lose this!” Despite her desire for her and her partner to return to their previous level of sexual intimacy and sexual activity, Terry described the *vicious cycle* in which she would find herself and her *inability to escape*:

Honestly, if I could get rid of the noise, the self-talk... when it comes to sexual intercourse, the *guilt*, of it not – of me feeling like I *should* feel desire and I don't. And the idea that I am *trying not to panic*, and then *beating myself up* because this is my husband that I chose to be with, and *how could I possibly feel panicky* with this man here

so close to me. And then it goes back to, you know, the desire, and *why don't I desire him*, but then it's *not him*, and, I can't... yeah, I can't, stop, it... if *that* could disappear, even if I could like just be blank and just, let whatever happens, happens, I think we would be okay.

According to Terry, this *battle* in which she found herself made it “*really challenging to get anywhere*.” She acknowledged that because her *mind was so busy*, this *disconnected her from her physical body*. She said, “I don’t think that desire feeling can come because I’m so much up here. I’m not paying attention to what’s happening in the rest of my body – so it’s that separation.” While she said she understood that the exercises in the OPES modules were intended to help her reconnect her mind and body, she felt that the “intellectual, existential, and philosophical stuff that goes with the cancer piece,” plus no longer having her ovaries, having no “primal drive” or lubrication, the possibility of pain, the memories and the physical scars, made it too *difficult for her not to let her mind just take over* – especially since “nothing is happening down here!” She explained that because her mind is “much more powerful” and busier than her body/ genitals that, “there’s no room for, for that connection... there’s NO space left.”

Terry’s psychological malaise also impacted how her husband responded to her sexually. What further added to the difficulty they experienced in getting past her *discomfort* and *avoidance* was what Terry considered her *husband’s intolerance for making her feel uncomfortable*. She noticed that if she got tense when he approached her in a sexual way, he would walk away because “he doesn’t want to hurt me.” Although she asked him to help her push through her discomfort, she said that he was not willing to because, “he can’t see himself being forceful;” he does not want to be “too domineering.” She reported that they didn’t get as

far in their relationship as she thought the program wanted them to or was hoping participants would get to.

Considering the absence of positive sexual experiences in Terry's narrative, it is not surprising that maintaining motivation to complete the OPES program was a challenge for her. An ongoing theme in Terry's narrative was how much the OPES program *felt like work*, especially considering her stated need, but inability, to get to the point where being sexual "felt natural" again. Terry reflected that working through the OPES program reminded her "*how mechanical this whole process really was*" which would make her angry, "because I didn't want it to be mechanical." She explained that she felt "*the whole process should've just been easy*" because she loved her husband and they were so close. But she often found the OPES program felt like "*homework!*" This, she explained, "is why I think I stopped sometimes and I just didn't do any of the modules cause I thought, 'I'm not doing this! This is ridiculous! Like it's just... I don't need one more thing in my life for work to do.'" Ultimately, she said, "there was *too much heavy stuff attached to it to work through*" along with "surviving in every day life." Instead, she said, "You just try and learn to deal with."

Although Terry did not devote much of her narrative to the topic of sleep, she reflected back on the time she participated in the OPES program, and recalled this was a period where she was *not sleeping very well* and that it was *hard for her to concentrate*. She recalled that she *had no remaining resources or energy to go "deep into anything."* She remembered how she would work on a module the hour before she went to bed, "because that's the only time in the day that I can get it in," and wondered if that was one reason why the OPES program "*felt more like work than anything else.*"

She recalled that the program was particularly challenging to complete what felt like a goal that would take a “*lifetime*,” in the intended 12-week period of the program. She explained that it was hard to go through the program in a “timely manner because there was so much that each [module] would bring out.” Amusedly, she admitted that the program would have been the most successful for her if she had been given two years to complete it.

Terry also experienced some *technical difficulties* while trying to complete the program (e.g., audio-recordings of the mindfulness meditations failing to work properly). When these problems disrupted her progress, she said it was particularly *aggravating*. She admitted, “the *technical difficulties that I experienced through part of it were a big barrier*... that, a couple of times, was just what made me almost go, ‘I’m so done with this program! Forget it!’ ... I don’t have time for this!”

Terry discussed some of the challenges she faced in completing Module 11 (Erotic Aids) in particular, which she attributed to: living in a small community, her hesitation ordering things online and having them mailed to her home where her children may ask questions, and lingering taboos about going to a “sex store.” While she was interested in this module’s exercises, she explained that she may have done these if she had access to more “sex-positive” stores, such as those in the Vancouver area, that did not feel so “cheap” or “sinful” as those in her own community which were located in the “worst part of town” with the “stereotypical neon sign.” She also was not comfortable visiting such a store in her area where she could possibly be seen by any of her students and/or their parents.

Motivations: What kept her going through the OPES program? Despite the challenges Terry experienced completing the OPES program, a number of things appear to have contributed to her successful completion, including being a *responsible person* – someone who is

accountable and follows through on her commitments. She was also motivated to complete the program in the *hopes* that it would help her *return to the level of intimacy she had experienced in her relationship with her husband* prior to ovarian cancer, and by her *fear of losing their previous connection.* Terry also was motivated to complete the program based on her desire to *model a healthy intimate relationship for her children.*

Terry's initial response to my question of how she experienced the OPES program was: "I think the reason that I was okay with the study was because I like to keep myself, um, *accountable* for my goals and what I'm working towards." Terry considers herself to be a "*goal-oriented*" person, who is dedicated to working towards her lifetime goals (e.g., *maintaining her marital relationship* and having "*more intimacy*" with her husband). Her sense of *accountability* and being a *high achiever* appears to have served as protective factors from her dropping out of the OPES program. In her story, Terry acknowledged society's pressure on women/ wives/ mothers to feel like we have "*to do it all, all the time*" to our own detriment. However, at some point in her life, Terry also became aware that only she could be responsible for *taking care of herself* by *balancing her tendency to "please others" with "taking care of myself... my own needs.*" In her words:

When I chose to do the program... it was me, *giving myself permission to do something for me...* That, okay, this is homework for *me...* it forced me to take that couple of hours to do something for me.... that was important for me, to finish.

Another contributing factor to Terry completing the OPES program was her being a *highly responsible person* which overlapped with how the program appealed to the "teacher" in her and her *desire to contribute to society.* She confessed:

I think I probably got through the program solely for the reason that I'm a teacher and I'm

trained that way. When I commit to something, I commit, and I do it. Whether it's going to be successful or not, I will see it through to the end, to make sure that I've given it my best shot, to see if it'll work, right.

The knowledge that by completing the program she *could help others*, also contributed to her perseverance.

Terry's *supportive husband* was a central figure in her narrative and their relationship is something for which she is very grateful. In response to my question about what kept her going despite the challenges she struggled with, she explained, "I think that my husband accepting me... I really appreciate that he is giving me the time and space to do what I need to do, and just trusting that it will all come together." She also added that his being "so forgiving," his patience, concern, and genuine "wanting what was best" for her also helped her carry on. She said that he was "more understanding" than she thought, "anybody ever would have been" in a similar situation. Terry commented that during her participation in OPES, if she had to deal with the additional frustration of having a partner who was not understanding, not willing to sit and have a conversation with her, or make the time, she said, "it would've been very easy to just say, "FORGET IT!" and drop out of the program.

Terry was also motivated by her *desire to return to that special place she shared with her husband before ovarian cancer*. She revealed:

I want, in some form, I want to be able to be in that space, again.... it really was like we were in this one space, together and the rest of the world just dissolved. And I don't feel like I find that anywhere else... and I'm hoping that, in some form I guess, maybe there's that internal hope, that I can reclaim a little bit of that.

Ultimately, it is Terry's life goal to try her best to *rebuild that intimate connection* she and her husband had. "I guess part of me feels that I kind of owe it to my husband and myself to try and, and carve out the best life that we can..." She desperately wants to *keep their existing connection going*, and she continues to *remain hopeful things will improve sexually*, and dreams about their future together, "80 years old and still holding hands."

Another strong motivating factor for Terry was her *fear that she would lose something important in her relationship with her husband* if she didn't keep trying. More than once, she also revealed her *fear of them growing apart* over the years, of *losing their intimate connection* that is so important to her, or of her husband leaving because they grew to be more like "roommates." Terry also fears how few years she may have left considering the mortality statistics for the type of cancer she had ("50-50 chance of survival in 3 years"). This added a sense of urgency to her desire to "figure out a way of creating space and time, now!" She proclaimed: "I don't want to die in this state. Like, I'm not quite... I'm not happy where I am!... I want to be, in a better spot... I will continue to work on it, but it's certainly the most challenging thing I've ever had."

Finally, Terry's desire to *be intimately reconnected to her husband* was also attached to her desire to *role model a healthy intimate relationship* for her children. This theme came up often in Terry's narrative as another driving force. She said:

I want my children to be looking and going that's the relationship that I want!... I'm desperate to have my children understand what a true, sort of, successful life is... it doesn't necessarily go 100% perfectly... we just try our best and anything you can contribute back is important. So *being that role model*, I guess is important for me.

Benefits experienced from participating in the OPES program. Terry discussed many things about the OPES program that she found helpful for her in beginning to address her sexual difficulties in the aftermath of cancer, including: *the opportunity for important self-reflection, being reminded to go back to the basics, and the opening of dialogue and increased intimacy with her partner.* In working through the OPES program Terry also felt she benefitted from the modules and exercises on *mindfulness and relaxation, information that addressed sexual misconceptions,* and further *resources which constituted a guide* for her in her life-long journey towards intimate (re)connection with her husband. She claimed the OPES program *continued to resonate* with her a year after participating, *keeping her accountable* to her goals.

Participating in the OPES program opened the doors and helped Terry make the time for *self-reflection.* Participating in the program reminded her that she “*had to work on the basics first*” and *pointed out the “keys points” she needed to work on.* When she was well rested, Terry found the OPES program “didn’t feel like it was work” and she had energy to spend on the “task at hand.” Terry appreciated the similarity between doing the OPES program and exercising: “You don’t really want to go ... but once you get there, you’re like, ‘Oh this is great! I feel so much better’.”

While Terry commented that the *content and structure* of the OPES program was good, she mostly discussed how the modules on *mindfulness and relaxation were the most helpful* for her, given where she was in her healing process. As she explained, “If I could get myself into a space where I wasn’t panicky and feeling traumatized and like this was work, I thought, okay maybe I will eventually get to these other parts... the sexual parts.” Because Terry had had previous exposure to mindfulness meditation in a cancer support group, she was familiar with these exercises in OPES and understood how they could be helpful. She recalled, “I started, sort

of, on a nightly basis trying to remind myself that ‘okay, this is my first step... nothing’s going to work if I’m not thinking straight’.”

Also when Terry was well rested, parts of the program got her excited, particularly the module on *relationship satisfaction and communication* (Module 7). She recalled:

I remember the [exercise] that asked us to have a conversation... it was hard to choose a topic because I wanted to talk about all of them... And it was interesting because we, we probably wouldn't have sat down in that context to discover that, but it was something that we needed to talk about.

So participating in the OPES program, she said, *helped create opportunities for important “deeper conversations” with her husband* that may not have happened otherwise. It helped Terry and her husband *maintain a level of intimacy and reinforced their goals of connecting and spending time together*. She said:

We *are* at the point where we’re still physically touching, in terms of we’re holding hands, and we’re hugging, and... we still talk about the fact that we want to get to a point where we’re physically intimate again ... it definitely helped that in that way.

Terry also referred to the *information she learned* on “responsive desire” (sexual desire that comes in response to arousal in a sexual experience) as being a more common form of sexual desire than “spontaneous” sexual desire (which, in our culture, is commonly misunderstood as being the more normal or healthy form of desire). Terry commented, “Like one of the modules talked about that circle of... we always think that desire has to come first, and then the rest will follow.” Although *learning that desire does not always happen spontaneously was helpful*, when reminiscing on her sexual life before cancer, Terry described spontaneous

sexual desire as being their norm – where sex felt “natural” and was not something she “had to force it through falsely.”

Terry explained that participating in the OPES program provided her with a “*12-Step-like*” program in identifying “concrete things” to think about and try in order to help her reach her goal of “getting more intimacy.” She said, “It gave me the opportunity to... remind myself that as hard as it is, and as challenging as it is, and as frustrating as it is, it is the path and the doorway that I want to be going in my head.” She said that her participation in the program keeps reminding her that: “I did that program. Why did I do that program? Well because this is where I wanted to go!” And am I there yet? No! So, I need to keep going. I need to do something else.” The practical suggestions made in the OPES program keep “popping up” for Terry (e.g., watching videos, reading books, talking to her husband, mindfulness), which she says, “makes it harder to avoid” her intimacy goals. In reflecting on the OPES program, Terry said: “I think that's what it did, is it... it was successful, in terms of putting me on the, in a direction that I think, in order to keep healthy relationship, I need to go.” She said she really appreciates having the OPES program’s resources and exercises to refer back to and try again when she is “in a space that I can do this!”

Terry said she was glad she went through the OPES program because it was “still resonating” with her even a year after she had completed the program. It continued to remind her, “I gotta keep working on that” because, she said, she still wasn’t in the place where she wanted to be (i.e., “we’re still not at the point where we’re back into having sexual intercourse”). Without the program, she admitted, “it would be easier to avoid because I wouldn’t be accountable.” In fact, she exclaimed, “Now, it’s not homework! Now, it’s my task that I have to do, that I want to do, for my own wellbeing.” She also felt less guilt associated with doing the

program after the study protocol because there was no longer the pressure of “someone waiting for the results.” Terry said, “Now, I have to take this on, and I have to do something with it because it's reminded me that that's where I'm supposed to be. That's where I what to go.”

Where she is now after participating in OPES. When reflecting on her current experiences after having participated in the OPES program, Terry discussed her ongoing *search to both reconnect various aspects of herself and reconnect intimately with her husband*, which she admitted, was hampered by *their inability to make it a priority* in their busy lives. Interestingly, during our interview, she became aware of ways in which she could *keep moving forward* and shared her ideas of what *next steps* she could take, which included *involving her husband more fully in her sexual rehabilitation*. She said she continued to *maintain hope* that things would improve as long as she kept her goals in mind.

During our interview, Terry was still processing her whole cancer experience and *searching for how she could reconnect the intellectual, emotional, and physical parts of herself*. She related her feelings of “disconnection” as being responsible for her *ongoing difficulty in reaching a “physically intimate space”* with her husband. She also realized this is not a simple process and wondered if perhaps she needs more emotional counselling.

Terry admitted that she and her husband were very busy and continued to *struggle with putting a priority on being physically and sexually intimate* with each other again – it “just seems like everything else gets in the way.” However, during our time together, Terry explored some ideas about what she could try, to *keep moving forwards* (e.g., playing music when she is alone with her husband in order to “quiet the noise” in her head). She also acknowledged that she needed to *schedule time to be intimate* with her husband, like a having a “date night,” and that she needed to “get over the idea that it's artificial.” Also, in reflecting on her experiences with

the OPES program, Terry realized that since she shared such a deep connection with her husband, she needed to *include him more in her sexual rehabilitation*. She reflected:

I think that, I need him there, in order to find that pathway again. I don't think I can do it through guided meditation... I think I need that physical connection of someone else being there. And that little bit of conversation that happens, you know, hearing somebody say that they love you, and this feels so good, and isn't this wonderful that we have this. Like, that's all part of that pathway, I think.

Terry explained that while she understood that the intention of the OPES program was to help her “to keep going on this path” she has chosen, she admitted that the modules did not actually get her to a place where she actually felt sexual pleasure again, or sexually reconnect with her husband (through sexual intercourse). She *maintained hope*, however, that *things will continue to improve*. She said she believes, and continues to teach her children, that one’s relationship with one’s spouse is “number one,” and that while challenging at times, “you have to keep it a priority.” She reflected that after participating in the OPES program, her sexual wellbeing and relationship is “still evolving... everything that I started with the program... is still definitely evolving.”

Advice on how the OPES program might have better met her needs. In response to my question on what she thought might have made the OPES program more helpful in terms of better meeting her needs, Terry made a number of suggestions. Considering the technical difficulties she experienced with some of the audio-recorded mindfulness meditations, she said a *CD or audio-file of these voice recordings* would have been appreciated. Terry also felt some of the *questions* (quantitative measures) used in the study and modules were *difficult to interpret*. She felt that that ambiguity lead to contradictory responses leading her to question the validity of

her responses. She also said it was difficult for her to simply rate certain statements/ questions on a Likert-type scale (e.g., *very likely*, or *rarely*) because “there's always a story behind ... some of those questions.” She wished that she could have *had the opportunity to explain*: “Why I answered this way,” or *been prompted to add a comment* to individual questions in order to lend her answers “more credibility.” Given the complexity of how she understands her sexuality and how so many things are interconnected, she felt that responding to quantitative measures on sexuality was difficult and overly simplistic – although she acknowledged the necessity of using quantitative measures in research.

Most importantly, a common theme running through Terry’s narrative was her need for a *longer period of time* to complete the program. Also, she wondered whether there could be *more flexibility* in the order in which the modules were delivered for each participant. For example, she stated that she needed the mindfulness exercises before she could move into the more body-centered exercises, while she thought others might put a priority on dealing with more physically-oriented modules/ exercises. She felt that allowing participants to choose the order in which they completed the modules may help the program be more successful for more people because, she said, “we are all wired differently.”

Lisa’s narrative. Lisa is a retired 71-year-old woman living in Vancouver, British Columbia with her “loving husband” of 28 years (second marriage). She has one daughter and two sons with whom she said she was very close. Lisa likes to keep quite busy with such things as quilting and a university woman’s club. At the age of 64, Lisa was diagnosed with Stage 2 colon cancer for which she received neoadjuvant radiation followed by surgery and a temporary ileostomy that was reversed about 6 months later. About a year after she was treated for colon cancer, Lisa had a stroke with expressive dysphasia (remedied through speech therapy). She also

mentioned at the time of our interview she was on anti-depressants. She participated in the OPES program about 4 years after her ileostomy reversal. It took Lisa approximately 42 weeks to complete OPES program and our interview took place about 15 months following her completion of the program.

Relevant background information. As Lisa narrated her experiences with the OPES program, she said it was important that it be made known she had been suffering from problems with incontinence since her cancer treatments and that she regularly had to wear Depends (adult diapers). She explained that her bowel problems were “a very unexpected kind of incontinence,” and everywhere she went she was sure to know where the bathrooms were. Lisa pointed out that, aside from one friend who had similar bowel distresses, people didn’t know this about her because: “it’s not something you talk about”. While Lisa’s husband was a physician, she didn’t think that even he could understand what living with this problem was like for her despite how understanding a person she said he was. Not only did she feel that her “handicap” had a profound and lasting effect on her, and her marriage, she felt it also influenced her experiences with the OPES program.

In addition to the predominant difficulties with having incontinence, Lisa pondered whether certain historical circumstances were also related to how she perceived herself as a sexual person and how she responded to the OPES program. She mentioned several times throughout her narration that she had a tendency to “put her walls up”, and wondered how this may be contributing to her sexual difficulties. For example, she briefly discussed that as a “fairly okay looking person,” she had often received unwanted sexual overtures throughout her lifetime, “even now as an old lady.” She also exclaimed that a “key thing” to possibly gaining further insight into her difficulties was that her first husband was a “philanderer” and this was likely

related to her “developing a big wall around that.” Also important for Lisa in understanding how she experienced and engaged in the OPES program, surfaced when she recognized that she also had a tendency towards evading thinking about painful events and emotions, as a means of self-protection. She explained that one of her coping strategies has been to avoid uncomfortable or distressing things, such as exploring her sexual self-perceptions and how this may impact both herself and her marriage. In her words: “I didn’t think of it until I came to you to tell you my saga. Because I’m so used to, the way I have survived all my [life] is to kinda compartmentalize, put it in a suitcase and park it somewhere.” During our interview, Lisa came to the realization that this avoidant defense strategy likely impacted how she progressed through the OPES program, particularly when program material or exercises triggered disturbing memories, thoughts, or feelings. Rather than dwelling on negativity or her own difficulties, Lisa described herself as someone who prefers to keep herself and her mind active on doing other things.

Reactions to the OPES program. Lisa began her narrative by telling me about her reactions to the OPES program. She started, “I had to think long and hard about whether I’d do it at all because in my head, family history, it’s not a topic you talked about.” She recalled that the only time anything sex-related was brought up in her family was after she started menstruating and her mother would constantly ask her, “Are you pregnant?” every time she was in a bad mood. Lisa reflected, “ I didn’t even have sex until I was 19!” She also admitted that sex was still not something she discussed with her immediate loved ones: “I have very close relationships with both my daughter and my husband, but we have our taboo zones.” This appeared to be related to some of her apprehension about what participating in a program on sexuality may bring up for her:

I was very worried about delving into this because sometimes it can bring things up that aren't comfortable for you. So, I took a chance, but that attitude of mine carried on through the process and I would leave it till you said to me in messages, say 'Are you ever going to do this?' kinda thing – They were nice messages you sent, and encouraging, so I would do the best I could and often go through it quite quickly.

Reflecting on how she was able to move past some of her initial resistance about starting the program, she explained: "I think that would be a cerebral thing... that it's important to being a whole physical being, and could be part of a growth and development thing for me." She also added light-heartedly, "And I do want to stay married."

Challenges faced when engaging in the OPES program. As Lisa narrated her experiences of working through the OPES program, it was evident that she faced many challenges as she progressed through the program. Foremost were the challenges she faced in *dealing with fecal incontinence* and the ensuing *physical distance that had grown between her and her husband*. Other challenges she recounted included her *fear and lack of interest in engaging in sexual activities*, largely due to her bowel distress, but also because *certain OPES exercises triggered upsetting memories or emotional discomfort* and she was simply *unwilling to complete some of the exercises*. Consequently, Lisa stopped participating in the program for long periods of time. During her participation, Lisa also *grappled with whether or not she felt she needed to talk to someone* (i.e., the OPES program coordinator) when she was feeling distressed.

A significant theme throughout Lisa's story was the profound impact her cancer treatments, and resulting *regular fecal incontinence*, had on her life and desire to be sexually intimate with her husband. She described the effects that her cancer treatment had on her body and sexual relationship:

The radiation is part of what causes the bowel distress, and the fact that the section of colon that they took away, the reservoir at the end, so once you have foods that activate your bowel, there's nowhere for it to be kept till you make it to the washroom.

So...unless you make an appointment to have sexual relations, it's always a worry, cause it doesn't, give you a time... Sometimes it's out of the blue. And I'm not sure what triggers it... But, once you have that stuff in your brain, it stops you from being that relaxed, like you need to be, to have relations with your husband.

Even though she clarified she had never had “the urge to go” during intercourse, she chalked this up to the fact that she and her husband didn't have sex very often in the first place. Lisa admitted that her bowel distress had contributed to a *physical distance that had grown between her and her husband* that she continued to have difficulty overcoming. She described a usual scenario that plays out in their relationship:

What happens in our relationship is, I sleep on the 6 inches of the bed, our king size bed, far away, and he always gives me hugs and cuddles, and I guess what you'd call sexual touching, but that always raises anxiety in me, rather than making me feel good. But, I have not told him that, cause I don't want to stop doing that... Catch 22...instead of reacting the way I think he is expecting me to, I have to quell down this ‘Leave me alone!’ annoyance.

Lisa assumed her husband could sense her irritation as she amusedly recalled his response: “I know I bug you.” In a more serious tone, she summed up what incontinence and being stuck in this “catch-22” was like for her: “It's very challenging. And you can't run away from it, it's there wherever you go, in your thoughts.”

Lisa said the *fear of her bowels evacuating during sexual activity* was constantly on her mind. The result, she confessed, was: “I’d be happy if I never had sex again... but I’m 71 and not 31.” Her *lack of sexual interest* was further hampered due to her inability to reach orgasm. She explained: “I think, for myself, there’s a real loss of interest in sexual activity... don’t seem to have, what do you call those things, orgasms anymore. At all, ever...” As she reflected on the impact these changes had on her, she said she honestly didn’t think that it bothered her that much, however, she said, “It only bothers me because I don’t feel I am giving what’s required in the relationship, the marital relationship. I don’t think he even knows that.”

While there were sections of the program that Lisa recalled including her husband in, she confessed that she was “selective” in choosing which exercises she told him about. Some of the *partner-involved touching exercises (i.e., sensate focus)* were particularly challenging subjects. She explained the reason she did not tell her husband about some of these exercises in the following words: “I think the truth of it’d be here is that, I was afraid of the touching would lead to sexual activities. In fact, I’m sure it would’ve. And so, I wasn’t wanting to do that.” Lisa said that she felt guilty “that there was some things I didn’t tell him cause I didn’t want to do, or didn’t want to discuss.”

Aside from the sensate-focus exercises, other parts of the program Lisa found particularly challenging, and stalled her progress for periods of time, included the more *sexually-oriented exercises* (i.e., Module 5 that included a genital exploration exercise, and Module 8 that included a self-sensate focus exercise) and the *use of erotic aids* (Module 11). For example, Lisa recalled her experiences with the module on erotic aids:

I remember trying to deal with the, uh, toys, ha... That was – they’re still in the drawer. I should clean them up and give them to you, to give to somebody else – none of those

things worked...tried both of them, but, annoyance comes to my mind. They were annoying.

She recalled that she reacted to this module by “*putting her walls up.*” In trying to understand this reaction to the module, Lisa recalled that these types of exercises brought up memories from her childhood – being 5-years old and “getting in BIG trouble for masturbating.” She reflected, “And I didn’t realize how much that had influenced my whole sexual career path... those early things.” She acknowledged that, “...you can change them, I know, if you work at it,” but admitted that her “particular handicap” made it hard for her to change. Lisa found the module on erotic aids particularly difficult and said, “I found it very hard. I almost thought of dropping out at that point.” Her lack of sexual interest and inability to orgasm, also contributed to a lack of impetus to complete these challenging exercises. Considering the distress that arose during these parts of the program, and her preference to push it aside, contributed to delays in Lisa’s progress through the program.

Furthermore, participating in the OPES program appeared to have *triggered some troubling things she had buried from her past* that Lisa acknowledged may have also played a role in her sexual difficulties, “...when I peel away the layers, I feel as if there’s other things that were not related to the cancer that I have to deal with too. Those are what I’m afraid of, I think.” While she did not disclose what she was afraid of, Lisa suggested the need for a module that dealt with topics, such as asking about how one learned about sex, because “they impact what your attitudes are now.” After a moment of reflection on her discomfort with some of the OPES program Lisa declared:

...your mind gets dragged off to, nasty places that you hid away... I’m going places that are little black holes for me that I don’t go to. And maybe that’s one of the reasons I did

it, because, I would like to resolve some of those issues, if I could. But I kind of...have given up thinking about that will happen and am just trying to make it as happy as possible.

She then added with humour, in reference to our interview, “And that’s what I am kinda feeling now, a little uncomfortable – is this over yet?!?”

As she worked at recounting her challenges with the OPES program, it appeared as if Lisa was in a similar catch-22 as she had been regarding not feeling comfortable speaking about her concerns with her husband – suffering alone with her own thoughts and fears. Lisa said, “It is very hard to do the program, locked inside of your head. And, with your demons. And the added demons of the physical handicap...incontinence.” One of the responsibilities of the OPES program coordinator was to offer support to participants who were having difficulties with the program. However, Lisa told me that she often grappled with the dilemma of accepting such an invitation. She recalled: “In retrospect, I know kind of, I can feel at night, sitting in bed with my computer, thinking, ‘I should go and talk to Erin.’ But I’d get up in the morning and forget about it.” This continued to be a source of regret for Lisa, as she later recounted her dilemma in wanting and needing to discuss her reaction to, and struggles with, the program, but feeling like she couldn’t reach out. “You said I could come to talk to you, and I should have... I didn’t want to, part of two-brain I think. This brain says I need it. This brain says, ‘Hell are you nuts!’” Using the OPES discussion board was also not something she said she could bring herself to participate in. She asked whether many people used the online chat board and admitted, “I went once and I thought, ‘Oh no, I can’t do this!’” which she explained was due to her own “unwillingness to talk about it.”

When asked what impact the OPES program had on her sexuality, Lisa said that participating in the program actually lead to an increase in her level of sexual distress: “I felt a little more distressed about the fact that I was not interested in sex. That I was *not* [interested], *that* was a concern. It was too be concerned about...” This truth, Lisa relayed, was a difficult one for her to come to terms with.

Motivations: What kept her going through the OPES program? Despite the challenges that Lisa faced in completing the OPES program, she identified some important things that contributed to her completing the program. One major focus was her *desire to stay married*, as she believed *sex was an important part of marriage* despite her disinterest in having sex. It also emerged that certain relationship dynamics likely facilitated her progression through the program, such as her *husband’s interest in the program*, their *mutual respect and support*, and their *shared humour*. Although she did not give herself credit for it, Lisa also revealed that she was a woman who was *willing to step outside her comfort zones* in order to try and recover her sexual interest. Her *hopes for change*, *wanting to improve her knowledge*, being a *responsible person* as well as wanting to help other colorectal cancer survivors were also contributing factors. *Being given permission to skip out of certain exercises* she said was helpful in encouraging her through the program.

It appeared that Lisa’s dedication to her loving husband and marriage was a significant factor in her motivation to complete the OPES program. It was her concern over her lack of sexual interest that encouraged her to participate in this program in the first place. She said, “It is hard to stay married when you’re not interested in sex. But, yeah, *I’d like to stay married*.” Lisa indicated that prior to participating in the OPES program, she and her husband did not talk directly about their discordant levels of sexual desire, but she sensed her husband was likely

reading her body signals. She recounted, amusedly, how they would banter back and forth: “He always says, ‘I love you more than you love me!’ I say, ‘DO NOT!’ In fact, we’re different and I’m sure he’s picking up on my walls. And of my fear over things.” However, Lisa believes that *sex is an important part of marriage*. She said, “Marriage is supposed to be about everything, and cause his job is high stress and focused on not the happiest of moments with people, and its nice to have a partner that is on your sexual level, I guess.” Lisa relayed that her husband was “very interested in being a part of this study too.” Lisa wasn’t always comfortable with his enthusiasm, but was very appreciative of his respect for her boundaries, especially since her cancer recovery. She recounted, “[he’s] just glad I’m here, and doesn’t put any sexual pressures on me, for which I am very grateful.” She shared a moment when her husband told her he did not want her to have sex with him out of a sense of wifely obligation when she really was not that interested. In her words, “Sometimes, I would, in the old-day words, come across, even when I didn’t feel like it, because I felt a duty. But, he said he didn’t really want me to do that. So that was nice too.”

Lisa recounted several moments between her and her husband during her participation in the OPES program, where they *used humour in their relationship to soften tension*, especially as they started talking about their sex life. For example, when they discussed her lack of sexual interest, she shared: “And we talk about it, banter about it, and, I tell him, ‘Never, never take Viagra!’ which makes him laugh.” When she finally talked to her husband about her fears of being incontinent during sexual relations, she divulged animatedly that his response was: “Never mind! Poop on me!” She laughed, “So we were able to talk to each other about those things.” She added, “He did good and... little more sex after that! Because it did take that pressure of worrying about cleanliness and all that stuff.” This was clearly a meaningful and encouraging

moment for Lisa – positive reinforcement for opening up to her husband and motivating for her to continue with the OPES program. Lisa’s desire to continue working on improving her sexual interest was also motivated by some *fear of losing her husband*. Her fear was likely exacerbated by not uncommon stories she recalled hearing from some of her friends who had had breast cancer. This was also a reason she claimed she was hopeful that the OPES program would make it to cancer clinics. She recounted the following:

But also, I know, breast cancer friends who have problems with, sexual difficulties and husbands who don’t like the fact that they don’t have intercourse anymore, or can’t deal with the whole sickness thing... and without much warning, just packed and gone. Which you don’t need when you are already stressed about your physical wellbeing.

Aside from supportive relationship dynamics, Lisa also demonstrated *courage to step outside her comfort zone*, despite her self-reported tendencies to “put her walls up” and protect herself from emotional/mental distress. According to Lisa, the fact that she decided to participate in and finish the OPES program, despite her apprehension, was indicative of her ability to step outside her comfort zone. She knew that participating in the program had the potential to bring up uncomfortable thoughts and feelings but she “took the chance” anyways. Also, Lisa did not let the possibility and consequences of unexpected public incontinence keep her at home or prevent her from doing the many things she enjoyed. Lisa also stepped outside her comfort zone by disclosing to her husband some of her sexual concerns and talking with him about sex, something they had not really done before. Also, despite her aversion towards the module on sexual aids, Lisa and her husband bought a couple different vibrators at London Drugs, and at least tried them. Lisa agreed with my observation that she met many of her challenges with

bravery. She replied, “Yes! I think that’s true... but I just tend to be very self-critical, so I forgot the things that were strengthened from my part too.”

When asked what kept her going through the program despite her struggles, she provided three simple answers: her *hope that things would change*, the fact that she was the *type of person who followed through on her commitments*, and because *she wanted more information*:

...honest answer, I was hoping for a magic thing to happen and things to change... I’m a finisher of things, too. I don’t like to kinda walk away when I’ve made promises. And the baseline is, I was *hoping for edification*... Edification. Learning... gathering, maybe to improve things. And I think it did that.

Although Lisa finished the program, she admitted there were some activities she had been unwilling to bring herself to do. Rather than staying stuck and abandoning the program altogether, *being given permission to skip out of certain exercises*, she recalled, was also helpful. When she struggled with the second last module on erotic aids and debated whether she would drop out she remembered saying to herself, “You can’t quit now cause you’re almost done!” Despite these challenges, Lisa reported, “I did feel glad that I persevered through it – that was a perk for me.”

There was also an element of *altruism* apparent in Lisa’s willingness to share her experiences as a means to (perhaps) break some of the silence surrounding the personal suffering among colon cancer survivors. She said, “...that piece of the puzzle, I think it is important for sharing with people too, because keeping [locked] inside with your demons is not healthy for any of us.” Lisa had this to say about her hope for the OPES program: “And I hope you get this module into the cancer wards too. Because I think, not just for colon cancer, I think it’s especially difficult for colon cancer patients – the body parts are so close.” Considering there

was a genetic component to her cancer, Lisa had a particular interest in being involved with colon cancer research considering her children could be vulnerable to this disease. In her words:

I've tried to share a little bit about what I was doing with my daughter but – in case this happens to her down the road...and I hardly ever talk about sex issues with my sons, and I told her just that I was doing a research project on sexual problems after the cancer.

Benefits experienced from participating in the OPES program. The main benefits for Lisa from persevering through the OPES program included the *opening up of dialogue about intimate and sexual matters with her husband* which resulted in an *increased level of closeness or intimacy* in her marriage.

Lisa acknowledged that her propensity towards “putting her walls up” rather than discussing things such as her fears and concerns about sexual matters with her husband was “an area that needed to be worked on in our marriage.” She concluded that the OPES program, “did have positive repercussions for sure,” in helping to *open dialogue* between Lisa and her husband, and *providing opportunities for increased sexual intimacy*. Early in our interview, she recounted how, during her participation in OPES, she “was a lot more conscious of the fact that we did talk about things together that we had not talked about before. I think that was a big plus.” She added, “And we did try some of the things that had been suggested. So that too was a plus.” The program encouraged her, “...to bring things out on the table that we never talked about before, ever,” especially important discussions about their sexual relationship. As a result she said, “for us as a couple, the program was excellent.” She summarized the impact participating in the program had:

You want to know, now what I am like after it, and I think there is some difference... I think the difference is that I did it with my husband, and I did deal with issues that I

hadn't done. *We* dealt with the issue of sex. We had not talked about it before. Not at all really.

When Lisa reflected back on that time, she recalled it was “a little scary.” But, she found her courage to share her experiences, such as her fear of defecating during sexual activity. Her husband was also gifted with the opportunity to reward Lisa for her bravery by responding in a loving and supportive way – allowing him to help quell some of her anxiety that she had kept to herself. She recalled:

He kept saying that, ‘I would rather have you here.’ Which was lovely, but I think the difference is that we have *another level of understanding* from sharing that... He knows things about me that he didn't know before, maybe not everything, but about how I'm feeling about it. Hence his comment about, ‘Go ahead and poop on me!’ That sticks in my mind and I do think about that.

Lisa willingness to risk sharing some of her internal world with her husband helped him understand what was actually going on for her, including when she “put her walls up” – thereby strengthening their bond through an *increased level of mutual understanding*. She said, “Maybe he had more understanding than I realized, but we hadn't put it into words.”

Despite her ongoing apprehensions throughout the program, Lisa reflected that this whole process was “enlightening” as it helped her and her husband achieve a *new level of closeness* they had not previously experienced. Lisa said the OPES program: “brings you a closeness that is important after this kind of surgery and so on, especially because it's a life changer kind of surgery.” As she reflected further on the impact that the OPES program had for her, she kept returning to this theme, which she believed also resonated with her husband, “... we have a closeness together that's good and we can laugh about things.”

Where she is now after participating in OPES. At the time of our interview, approximately 15 months after Lisa completed the OPES program, she reported that there continued to be a *closeness between her and her husband*, as well as a *new level of openness about their sexual relationship*. However, Lisa said she was still struggling with *incontinence and dietary concerns, disinterest in sex and ongoing distress that remained unresolved*.

It was clear that Lisa and her husband continued to share *a new level of closeness and openness about their sexual relationship* after she completed the OPES program. Close to the start of our interview, Lisa recounted a brief discussion she had had with her husband the very morning of our interview, about whether he thought the OPES program influenced their sexual relationship. She recounted, “I asked him this morning ‘Do you think it made a difference?’ And he said, ‘Yyyyy... Once in awhile!’” The meaning she took from his hesitancy was due to the fact, she said chuckling, “he still would like more sex.” However, Lisa reported that she and her husband were still having sexual relations. In her words: “I’m 71, so... both of us, we’re still sexually active, once a month.” However, Lisa went on to describe what usually occurs between her and her husband and acknowledged that *she still has no real interest in sex*:

Any sexual encounters are usually started by him. So usually I’m going, ‘No I’m tired!’

But once in awhile, I give in! HA! – I’m sure those are words he heard, or would be

horrified to hear, but they are the truth for me. Its truth for me.”

When speaking these words, Lisa’s tone turned sombre and she fell quiet. She confirmed that this was bringing up some feelings for her, and after a long pause she said, “Well, I’m just looking around for words, and the word that’s coming out is disappointment. *Disappointed that I, can’t be, the way I was.*” She confirmed that she was still likely processing some grief over things no longer being the way they had been before she had cancer. She continued:

So now I want you to ask me a question because I am lost... on the grief thing, and I don't want to stick there... Because I fight it all the time, obviously. I didn't think about that, but you're right... I told [support group] about my problems with my bowel and I can feel tears welling up. I didn't need Kleenex because I take anti-depressants, and I don't cry, even when I deserve to.

Upon reflecting back on her experiences of working through the OPES program, and recalling those times the program triggered some distress, Lisa relayed that she continued to have *regret that she did not take the opportunity to seek further support* by talking to me, as the program coordinator, at that time:

But more than once through it I felt like, you offered many times to, have me talk to you, but I – because of my technique of blocking things out, and stowing them away, I didn't want to come and talk about it. But I think I should have...

It was apparent that Lisa continued to struggle with some difficult things that she was not sure she wanted to deal with, or to talk to someone about.

Advice on how the OPES program might have better met her needs. The theme of *increasing interpersonal support* as an important addition to the OPES program was apparent in Lisa's narration of her experiences with program. Lisa queried about the OPES program: "The idea with the program is to make it so that it can be online it can be totally without human contact? I think it might need a little piece of human contact." She shared some of her thoughts on how the program could increase its participant support in a way she would have been able to accept. She reflected:

For me, if you said, now it's a sixth one [module]... I'd like to meet you and see how you are doing with it. I would have come then. But when it was left up to me to decide, I

decided – I did think about it really back and forth... and the thought about all the therapies, things I've done in my life, and decided, 'I'm old now, I don't need to do anymore.' But honestly, I think I should have.

During her narration, there were a few instances when Lisa talked about two separate support groups she had participated in – one, an online cancer support group, and another, an in-person support group on dietary difficulties. She discussed that she found great comfort in, and value from, the validation and support she received from these person-to-person interactions. From her experiences with an online chat room for colon cancer survivors, Lisa did acknowledge that while an anonymous chat room is not an impossible place to talk about one's sexual concerns, she admitted “for the sexual, I-must-not-talk-about-this attitude, it's harder.”

Paula's narrative. Paula is a 60-year old retired woman living in the lower mainland of BC with her husband of 30 years with whom she has one adult son. She described her marriage as very good, the last 10 years of which had been especially happy. She has a very active lifestyle and volunteers with various community organizations. Around the age of 40, Paula was diagnosed with breast cancer for which she had a mastectomy and reconstructive breast surgery with no known complications. In late 2009, she was diagnosed with colorectal cancer that was treated by surgery, chemotherapy, and radiation. She also had a temporary ileostomy for a year after her surgery, which was surgically reversed two years before she participated in the OPES program. It took Paula approximately 17 weeks to complete the OPES program. She completed the OPES program modules approximately 16 months prior to our interview.

Relevant background information. As Paula narrated her experiences with the OPES program, it was evident to her that her experiences of living with an ileostomy prior to participating in OPES and sex being a low priority in her life and marriage likely influenced her

attitudes towards, and experiences with completing the program. Her having a supportive husband also emerged as being an important part of her life and cancer recovery.

Paula spent a significant portion of our interview narrating her experiences of having a temporary ileostomy – an aspect of her experience of cancer that seemed to have a profound impact on Paula. She described this period as being “*a very difficult time*” of her life. Having had breast cancer, a mastectomy, and breast reconstruction 14 years prior to bowel cancer, Paula said, “was nothing, nothing in comparison” to having a stoma and ileostomy that involved physical problems (i.e., pain, discomfort, and leakage) and psychological difficulties (i.e., embarrassment and poor body image). Paula shared some of her experiences:

But the stoma, is a very different thing... it really embarrassed me. It's just a very difficult thing.... There's the, “Will people see under your cloths? Is it going to leak?” And sometimes it does, in most embarrassing ways. You can be in a pub, for instance, and then you think, ‘Oh my God!’ and it's soaking wet there. And you haven't noticed it for 10 minutes. But I can guarantee you someone else has! So it's very difficult... You've got to take all your paraphernalia with you in case there's a leakage, and that impacted me way, way more in the sex department than the mastectomy.

Aside from the embarrassment, Paula experienced a lot of pain and skin irritation from the ileostomy. She recalled there were days when her skin was so raw that she just couldn't “get it to say on” and occasionally she had to go back to the hospital for help getting the ileostomy bag reattached. She described this experience:

When you have that apparatus... it's stuck to the skin!... the acid, if you have any kind of leak at all, it burns your skin. And my skin was in such a state at one point that the bag wouldn't actually stick to the skin. It would not! Because my skin was weeping so much,

and it was literally, almost breaking into holes; it was so incredibly sore.

Having to frequently empty the ileostomy bag during the night also disrupted her sleep and her husband's sleep, and their sharing the same bed. She recalled:

I never slept for the year I had it, I never hardly slept because I was getting up, how many times a night to empty that thing... four or five times to empty it. So, it was...so it really interrupted his sleep. So often I would sleep down here [on the main floor of their home]...He was very sad! I know he was very sad.

Paula reflected that her husband did not want to see her stoma/ ileostomy, but she didn't "blame him at all" nor did she "have any angry feelings towards him" because, she said, "I didn't like it myself." Paula asserted: "If you have a stoma, you don't feel attractive. You just don't!...You lose your sexuality, I think, when you have a colostomy or an ileostomy." She agreed that during this time, she felt like she lost a sense of herself as a sexual person, at least in part, due to constantly feeling unclean. In her words:

And I always felt *dirty*... I must have used the shower I don't know how many times! I just kept washing all the time, like it almost became a bit of an obsession... you just always feel dirty! I'm sure other people, with a colostomy or an ileostomy, feel the same way. You just don't feel clean.

Paula admitted that for the year she had an ileostomy, "we never had any sex at all because I did not feel comfortable having sex with an ileostomy, and I don't think my husband did either." She wanted me to understand that she was not complaining. Rather, she just wanted to emphasize the negative impact the experience of the ileostomy had on her sexual relationship with her husband and on her sexual self-perceptions. Paula explained:

Even that movement itself would be very uncomfortable if you had bad skin at the time.

And I'm sure everybody who has a stoma has had that problem... Without any leakage, or whatever that happens. Just, not nice! It is very challenging."

Another period of sexual abstinence followed the surgical reversal of her ileostomy. Paula recalled:

You have to learn how to control your bowels again. It doesn't come naturally. You have to learn to do it again... you have to go to the bathroom a lot, and you get very sore and all the rest of it. It's a very miserable experience actually.

Considering these complications, Paula began her narration by pointing out there was "quite a gap" where she and her husband "did not have sex" – what equated to be around a 2-year period from her commencing cancer treatments to fully recovering from the ileostomy reversal. Despite the impact cancer had on their sexual relationship, Paula concluded, "we managed quite well" in part due to the fact that her *husband had been an important source of support*. In her long recovery period, during which they were not having sex, she recalled having felt sorry for her husband. Reflecting on that period of their lives she said: "I think both of us just realized it was just not important in relation to me getting better." Paula also explained that *sex was just one aspect of their marriage*, that it was *not necessarily a significant part of their relationship*. In her words, "there were other things besides the sex in our relationship. It's nice, but it's not important." For example, what was important in their relationship was their shared sense of humour. She said this was, "way more important for us than often anything else, because we laugh at the same things." Paula also explained that, rather than having "sex" per se, intimacy was and continues to be a higher priority in their relationship. She disclosed how their always having shared the same bed was important in maintaining their intimate connection –

which was one of the reasons it was difficult when she felt she had to sleep in a different room during the period of her ileostomy. In her words:

Like every day at the end of the day, we have that, where we'll cuddle and whatever at the end of the day. And in the morning ... when we wake up, one will go and make the tea, and bring it up to bed. So we always have our tea in the morning and we talk about what we're going to do that day...So that is intimacy and that is very important to us.

Several times throughout our interview, Paula reiterated that knowing her ileostomy was only temporary also helped her cope with its associated challenges and likely mitigated the stress this had on their intimate and sexual relationship. She said:

I knew it wouldn't be permanent. So I didn't think, "Oh, this is terrible! This is terrible for my life, and for my marriage."...I always thought to myself, "Well this is just temporary.... just a, not very pleasant experience, but it will be fixed!"

Paula believed that if she had to have a permanent ileostomy she: "would have had psychological problems, I'm sure of it...I would have needed psychological counselling."

Paula explained that the reason she decided to participate in the OPES study was because her son is involved in research at UBC and she understood that there was a need for people to participate in studies. She said, "I thought well... maybe this will help you with your studies, my son is at UBC as well and they need – it might help somebody else." She also commented several times that she did not participate in the OPES program because of any psychological problems, as these were no longer an issue for her since her ileostomy had been reversed. In her words: "the reason I agreed to do the study... for me once I was better and I didn't have the ileostomy it was never about the psychological stuff, it's about the physical stuff because it actually hurts to have sex."

Reactions to the OPES program. Paula appeared to be somewhat self-conscious about what she had to offer about her experiences with the program. Our time together was punctuated with many long pauses and silences. She repeated a few times that she “couldn’t think of anything else,” or that she “wished she had more to share.” All in all, Paula explained she did not have a whole lot to share about her experiences with the OPES program, or her sexuality. In her words: “I don’t really have much to say because as I said with me it was always, about the physical thing, you know, it is quite uncomfortable for me to have sex, even now.”

Paula was clear from the beginning of our interview that before being introduced to the OPES program sex was something she had never really thought about. She explained:

I’ve been married for almost 30 years. It’s not something I sit there and ponder over... It’s just another side of my marriage... I’ve never had anyone ask me about sex... I never really talked to anyone about it really, not even my husband. I mean it’s something that happened in our marriage, but it’s not something we ever talk about.

Given this context, Paula’s initial reaction to the OPES program and the pre-program study questionnaire was one of surprise – surprised at the content and at her reaction to it. She explained with amusement:

I was surprised by some of the questions... because I’ve never done any sexual study in my life, right! And then...not shocked or anything like that, but I was just thinking, “Oh, well, I’ve never even thought of that!” because I’ve never really thought about sex!

In response to my question about what was surprising to her, she responded laughing: “Oh well, the surprising thing is that I’ve never really thought about it before!” The impact this realization led her to question: “Should I have thought more about this in my life, or does it not really matter?” When she recognized during her participation that she also had never really talked to

anyone about sex, she recalled contemplating, “Should I be talking to someone about sex? Does it really matter?” She eventually concluded that no, talking or thinking about sex just didn’t really matter to her: “I’m going, at the end of the day, ‘No!’ right.”

Challenges faced when engaged in the OPES program. In Paula’s narration of her experiences of completing the OPES program, she did not recount having any particular challenges directly related to the program, other than some initial *discomfort in discussing the topic of sex*. However, she discussed having *some physical problems that impacted her having sexual intercourse*, such as vaginal pain and gastrointestinal problems. She also talked about how *participating in OPES brought up feelings of guilt about her attitudes towards her ileostomy*.

Paula explained that since her ileostomy had been reversed, her concerns were about her physical difficulties that made intercourse problematic. She said: “It actually hurts to have sex.” Vaginal pain made sex less pleasurable but Paula explained that she was coping with this in her own way. She said, laughing: “I just uh, grit my teeth sometimes, and just think, ‘Well, huh, breath deeply, think of England!’” She believed her pain was likely due to scar tissue from the surgery as her tumour was very close to the vagina wall. Paula seemed somewhat surprised to hear from me that vaginal pain is not an uncommon complaint after receiving radiotherapy and/or surgery for gynaecological or colorectal cancers. In addition, Paula referred to having ongoing problems with flatulence/ gas and frequent bowel movements since her ileostomy had been reversed:

Not to do with the study, but...well after you’ve had all that surgery, even when you are good, like I am now...you do have a lot of problems, like you can get gas and you go to the bathroom a lot, and all that, so I was having quite a bit of that. So that’s another

aspect that when you have sex, sometimes you're gonna pass gas and that's just part and parcel of the surgery and what happened.

During her participation, Paula recalled that she often reflected on the time she had her ileostomy. She noticed that sometimes troubling *feelings of guilt or judgement towards her negative attitudes towards having an ileostomy* arose. On the one hand, participating in the program helped her feel validated in realizing many other people living with a stoma had similar physical difficulties to her own. On the other hand, knowing that others had to deal with these things for their entire lives somehow made her own suffering seem more trivial, especially since she knew prior to the operation that her doctor was going to reverse the ileostomy in a comparatively short period of time. In Paula's words:

That was like a seesaw because every time I started thinking about it, all these people having problems like you, and then I felt guilty for thinking about it, cause I'm thinking, 'Why are you even thinking about this?' Cause people have got those things all their life! So I kept beating myself up...because I felt guilty that I was even, because it is *so* difficult to live with those things.

Although the difficulties she experienced when she had an ileostomy occurred prior to her participating in the program, Paula revealed that she could now understand how anyone with these types of experiences would avoid intimacy or be unwilling to address their sexual problems:

I just understand the physical problems that you have, and also the body image problems, and I got into that bit of obsessive washing all the time, which was a bit weird... so I do kinda of see how they could get into saying, 'Okay... I don't want to have anything to do with sex at all' because... don't take this the wrong way, I'm not saying this, but it's

almost easier not to have sex and you don't have to face the problems...I'm pretty sure that's what it was for me, right... Well, I wasn't feeling well and I'm just thinking, 'I have to concentrate on just getting myself back to normal and I can't deal with all these other problems here! I have to deal with this box first! And we tick that box, and then we get over to that box!'

When asked directly if she experienced any challenges with the OPES program, Paula responded: "No, I don't think so. I mean it was a challenge in itself because it was a new experience...it was good in the fact that it was different. So I didn't really find any challenges or 'I can't do this.'"

Motivations: What kept her going through the OPES program? Considering the lack of psychological or physical challenges Paula experienced in terms of working through the OPES program, finding motivation to complete the program did not appear to have been a problem for her. As Paula narrated her experiences, a number of things arose that appeared to have further contributed to her ease in completing the program. These included *self-reliance* (or self-determination); *having realistic expectations of her partner*; *her ability to go beyond her comfort zone*; *her enjoyment of trying new things and working on a project on her computer*; and *being a committed/ responsible person*, as well as *having a clear understanding of what participating in the program entailed*.

Participating in the OPES program was a very individual project Paula decided to take on herself without involving her husband. When it comes to solving her personal problems she said, "*I always have to find the answer for me.*" She explained that she did not necessarily need to discuss these things with her husband. She said, "It has to come from me. I have to get the answer for myself... I work it out." It appeared as if being *self-reliant* was likely helpful

considering Paula's husband was not involved in her participation with OPES. When she spoke about her husband, Paula portrayed a *very accepting attitude towards her husband's lack of participation* and his unwillingness to discuss sexual matters with her. She explained, "my husband has never been comfortable talking about sex, and I knew before I did the study he wouldn't participate... And that's perfectly fine with me because I knew he wouldn't, because I know my husband, right." This did not mean that Paula did not attempt bringing up the topic of sex with her husband. For instance, she recounted that they were able to discuss her having pain with intercourse and explored ways to work around it, which often ended up with Paula and her husband "in fits of laughter about it!" She reflected with amusement, "I did try to initiate some conversations but, my husband... he likes his pub, his beer, and his home and his cat! And he's very happy that way and there's nothing wrong with that!"

Attempting to engage her husband in discussing sex, even though she knew he was not likely to reciprocate, is one example of how Paula demonstrated her ability to *go beyond her own comfort zone and try new things*. Her decision to participate in the OPES program, despite her initial ambivalence in doing so, is another. She admitted:

I thought about it a lot before I did it, before I went on the computer, and I was asking myself, "Do you really feel comfortable doing this?" Right. And I just went, "well, I don't feel totally comfortable doing it, but, there's a study going, I've had the cancer, I might as well share my experiences or whatever."

Another prominent example of her *openness to trying something that she had never dared to before*, involved her purchase of her first vibrator. Reflecting back to the module on erotic aids, Paula recalled:

I certainly never had a vibrator before and then you had to go out and buy one! And I thought: ‘*OH MY GOD!*’ And then it said, “It’s all right, you can get one at London Drugs”... And I said to my husband, “I have to get a vibrator for this study!”... I had never thought of getting one before!

Because she understood this was part of the program’s homework, she recalled thinking, “Well it can’t be bad!” She shared that she had not previously bought a vibrator because she was worried “it might insult my husband,” but she learned that he did not seem to be bothered by it.

This ability to enter previously uncharted territory also complimented Paula’s *enjoyment of trying new things*. Paula described herself as someone who *likes “new experiences”* and “always loved meeting new people” – aspects that made her life interesting. She added: “I like new things, so the study was just a *new* thing for me.” Also, she revealed her satisfaction about *engaging with her computer* again, something she had not spent as much time doing since retiring from her job. She said, “I don’t go on it much, since I left work. So doing the study... it was kinda like, ‘Ooo, I’m on the computer again!’... just a different aspect of my life I suppose.”

According to Paula, one of the main things that contributed to *not* dropping out of the OPES program was the fact that she is a *committed type of person*. She humbly described herself as “the sort of person, and now it sounds like I’m boasting, but I’m not boasting... if I commit to something, I will finish it... once I make a commitment, I pretty much 99.5%, I will finish it.” She clarified that this was not about dedication for her, but simply the way she has always done things. She clarified that *knowing what was expected of her* as a study participant before she started the program also helped her to be mentally prepared for the commitment. In *knowing the time commitment* that was involved she said, “I kind of make a mental note of when I was going to do it in the month. It didn’t always work out that way, but... yeah.”

Benefits experienced from participating in the OPES program. Paula recounted several benefits she felt she derived from participating in the OPES program. Many of these centered or overlapped with the theme of *novelty – thinking about sex was a new experience* for her as well as acquiring an *increased level of comfort in discussing sex*. While these changes were not necessarily “earth-shattering,” Paula stated that they “*opened new possibilities*” for engaging with this topic which in turn *added further variety to her repertoire of interests and knowledge*. Participating in the OPES program also provided *confirmation that many other cancer survivors were experiencing similar difficulties post-treatment* as those she had dealt with. In working through the OPES program, Paula found the modules and exercises on *mindfulness and relaxation* were particularly helpful for her in dealing with painful intercourse. She also appreciated the suggestion of *using a vibrator*.

An overarching theme in Paula’s narration of her experience with the OPES program was *novelty*. Participating in the program *brought her attention to the topic of sexuality* for the first time, and provided an opportunity for her to reflect on how relevant or important sex was in her life and relationship. She said, “Yeah, it was good. The study was good for me because I’ve never, as I said, I’ve never thought about it before. It opened up my eyes. I’m sure other people talk about sex... yeah, it opened up my eyes.” Paula felt the most important benefit that she took away from participating in the OPES program was *growing more comfortable discussing the topic of sex*, a theme repeated throughout her narration. She said, “the study helped me in myself, because, number one, I’ve never spoken, really, about sex and not really even to any of my girlfriends... So it helped me in that respect... now I wouldn’t feel uncomfortable talking about it.” For example, she recounted how she was able to talk to one of her girlfriends about the program: “I did mention to one of my friends about... the study, and she was asking me about

it... So I did tell her what it was about, and whatever...I wasn't embarrassed but we did have a giggle about the vibrator!"

Paula felt this *newfound level of comfort* in discussing sexual matters had a positive impact on her marriage. She explained, "Well, there's certainly a *new aspect of openness*. Now I would, you know, I feel quite comfortable telling my husband what I was doing in the program. Yeah, I think it helped with just being more open about everything." She thought about whether or not she should start a dialogue with her husband, but confirmed that he was still not comfortable talking about sex. However, she said that participating in OPES, "*opened up the possibilities*" - opening up her mind to new things.

Paula found that her experience of participating in the program and finding herself being able to discuss sexual matters was "*quite enlightening*." In fact, she confirmed that it was like a liberation of sorts. She explained, "the fact that I was on the computer and I'm telling somebody at the other end all these intimate details, like, 'Oh! Oh! I am capable of this!' [I'm] not just like this little person, that's all wrapped up. I've broken out of my package!"

The novelty of thinking about sex and feeling comfortable discussing sex provided Paula with access to *new possibilities*. This was another valuable outcome she experienced from participating in OPES because it *added another dimension to the breadth of activities and interests Paula enjoyed having in her life*. She went on to explain the impact that this change had on her life:

"...it's just another aspect of life... if you can converse about a different subject it's always beneficial, cause the more knowledge you have the more you converse. I guess, the more educated you are, I suppose...going back to variety is the spice of life, right, so I'm always doing different things... So it is beneficial and good in my life, but it's just

one aspect of my life...I enjoyed doing the study, just because I thought I had broad, broader spectrum... of looking at things.”

It was evident that participating in the OPES program clearly evoked a lot of reflection for Paula, on her experiences of having an ileostomy. Acquiring the awareness that other people experienced similar difficulties as she had helped *validate and normalize Paula’s experiences with having an ileostomy*. In her words:

The program helped, yeah it did. Because, I think one of the biggest things... I always wondered, people with stomas, what they go through, and I’m thinking to myself as I’m doing this, that these other people, they’re having very similar experiences. Right. I think that’s what brought it out...the awareness that other people were having similar problems. Because you wouldn’t be asking the questions, right, if there, if nobody was, right?

Participating in the program helped her feel less alone in her suffering. She added, “if I hadn’t have done the study then, you’re not so aware of what everybody else is going through.” She also said that participating in the OPES program helped her with the dissonance she had experienced between remembering having hated her temporary ileostomy and feeling guilty knowing others had to cope with it for their lifetime.

Paula recalled two aspects of the OPES program that were particularly beneficial – the *suggestion of using a vibrator* and *the modules on relaxation and mindfulness*. Because she found sexual intercourse difficult due to her vaginal pain, using a vibrator helped improve the pleasure she experienced in sexual activity – something she had not thought of before. She shared: “Yeah, it’s pretty good! I don’t find it necessarily, um, well yes, it is better for me now because it actually hurts to have sex.” She later added that although using a vibrator felt better

for her at that point in time, she also admitted that “it’s not as intimate as, as actually having sex with a partner.” Paula also recalled that the *relaxation exercises* in the OPES program were “really good” in helping her approach the potential of pain with sexual intercourse in a different way. She laughed as she described her experience with relaxation: “That did help actually...because I am like, instead of going, ‘Oh God! Ah, it’s going to hurt!’...okay now, the exercise is doing this, you got to do that! ... Yes. Very helpful... Yes, helping me relax, yeah.”

Paula summarized her experiences of the OPES program in the following words: “I wouldn’t say I enjoyed doing it, but it was enjoyable in the fact that it was different for me and I enjoyed working through a task on the computer and like that.... I did not find anything that I disliked in the program.”

Where she is now after participating in OPES. When reflecting on her current experiences after having participated in the OPES program, Paula stated plainly, “at the moment *we’re still not having sex a great deal, but we do have sex.*” This was partly due to *ongoing vaginal pain* when she tried to engage in intercourse, which she said she managed by using a lubricant and the relaxation techniques she learned, as well as “some Extra Strength Tylenol!” She also shared why she and her husband were *not having as much sex as perhaps they think they should’ve been* having, was that they both “lead such different lives.” She said she and her husband were like “two ships passing in the night.” She explained:

We decided, because we should be having sex a bit more, we decided to go on a couple’s vacation.... whenever we’re on holidays we always have a lot of sex...when we go on holiday, we’re together all the time, and it can be quite romantic... we’re just by ourselves. I think the holidays are going to fix us.

She also expressed gratitude for being able to continue to share and *enjoy other interests she and her husband had in common* such as live music and dancing.

Paula also reported cheerily that since she had her most recent colonoscopy a few months prior to our interview, she was *no longer having gastrointestinal problems* (i.e., passing gas and going to the bathroom a lot) that had been bothering since her ileostomy reversal surgery. She said, “So I’m no longer having the problems with gas and... all that stuff. And I’m not really going to the bathroom a lot at all, so that’s very, very good. Nothing to do with the study, but it’s – that cuts down on the psychological whatever, you know, don’t have to worry about it.”

Advice on how the OPES program might have better met her needs. Paula offered no comments or advice on how the OPES program could have been improved. She remarked, “No, I don’t have anything to add. I thought it was a pretty good study.” She also felt that the timing of her participation in terms of her cancer recovery (about 2 years after her ileostomy reversal) was “about right” for her.

Pam’s narrative. Pam is a retired 60-year old woman living in the lower mainland of BC with her husband of over 40 years. They have two adult children and four grandchildren. Before retiring at age 50, Pam had a very successful career in financial information technology. She described herself as being actively involved in life – busy with the family cabin, her grandchildren, and living her life to the fullest. When Pam was around 52 years old, she suddenly started experiencing abnormal menstrual cycles – heavy bleeding and clotting lasting for days to weeks, with increasingly painful cramping, that occurred over a two and a half year period. After Pam finally convinced her doctor to refer her to a specialist, to her shock and dismay, tests indicated that she had grade-3 endometrial cancer for which she received a laparoscopic-assisted vaginal radical hysterectomy, total pelvic lymphadenectomy, and

oophorectomy. As the cancer was Stage IIIc (late stage and fast-growing), surgery was followed by aggressive adjuvant treatment consisting of four rounds of chemotherapy, followed by 5 weeks of full abdominal radiation plus two cycles of vaginal radiation (brachytherapy). Pam completed all cancer treatments in six months and participated in the OPES program approximately 2.5 years later. It took Pam approximately 52 weeks to complete the OPES program. Another 2.5 years after completing the program, Pam participated in this interview.

Relevant background information. Pam emphasized that her cancer diagnosis had a profound impact in terms of her and her husband's lives and relationship, her awareness of her own mortality, and empowering herself to be a stronger advocate for her own health. Interestingly, Pam believed that her cancer experience had much less of an effect on her sexuality.

A central theme in Pam's story was the love and support shared between her and her husband. As Pam narrated her experiences with cancer and the OPES program, it was obvious she believed that her "loving" husband played a crucial role in her recovery. Their enduring love and solid, supportive relationship clearly influenced how Pam approached and worked through the OPES program. She highlighted how important her husband was in her cancer journey: "...he was a big, still is, my biggest supporter." Pam and her husband were "high school sweethearts" – each other's only sexual partner, and she considered them to be "pretty much soul mates." Her voice cracked with emotion when she shared: "So no better person to ride this cancer journey with... I don't think I could have gotten through it without him. Well, I know I couldn't have."

When Pam was diagnosed with cancer, she recounted how devastated they were; their worlds rocked to the core. She described how her cancer diagnosis impacted them:

I think we were so emotionally distraught working through the cancer, we were on a whole different plain. We would *cry* together, for *hours*! Go to sleep crying, thinking we weren't going to be together...nothing draws you more intimate and close than that.

Going through the treatments...that was such a close time.

Pam acknowledged that cancer also greatly impacted her husband. Pam's husband retired a year early from a successful career in banking and became her devoted caregiver, and cancer treatment manager. Pam remarked, "He had as big of a recovery as I did, really! His world crashed in front of him too. And, he quit his job! His daily life changed, his outlook changed, he faced it pretty square too." Pam stated that cancer definitely changed their relationship, which at the time of our interview was still "not 100% back." However, Pam looked forward to "growing older with the same guy." She added, "Getting to that understanding, and that comfort level. I can't imagine that happening with somebody else. Because we are just so in sync."

Pam reported that she and her husband, "always had a really good and healthy sex life." However, over the 2.5 years that her gynaecological symptoms increased in severity, their sexual relationship was increasingly limited to the point where they were only "having sex one week out of four," and even less frequently when her pain and bleeding became too extreme. Once she got her diagnosis, Pam did not recall receiving a lot of information on how her sexual functioning could be impacted by a hysterectomy. Pam discussed how her and her husband were anxious to resume sexual intercourse soon after she had her surgery. She described the following with some amusement:

There's a time after the hysterectomy where you wait, and I don't remember how long we were instructed to wait, but we didn't wait. And I'll tell you why – was because, first of all, we hadn't done it in a *long* time...but more than that, we were curious as to what had

changed. Like did I still have a vagina?...How much did they cut out of there? My surgeon did talk about the vault being changed. We were concerned. So, we didn't wait. And I remember the day we did it. It was very shortly after the surgery. Probably shouldn't have done it. But we were sure pleased with ourselves that everything still worked.

Pam recalled how they were both delighted and relieved that everything seemed to be in working order, and said that their sex life picked up remarkably after her surgery. The removal of Pam's reproductive organs, however, put her into immediate menopause, leaving her uncertain as to whether her insomnia and vaginal dryness were due to the cancer or menopause. After having completed radiation treatment, Pam had also been instructed to use dilators for her vaginal rehabilitation. She said the radiation created "a lot of scar tissue and shortening the vaginal vault." Although she and her husband used these together until they were able to have sex again, she did not recount this part of her recovery as an enjoyable experience, saying she much preferred to have sex with her husband. After completing all her cancer treatments, Pam recalled that she no longer had the same level of sexual desire she had prior to cancer, although this was not a prominent theme in her story. Rather, her recollection of being interested in the OPES program as a way to "give of herself" by participating in the research investigation was more salient.

Challenges faced when engaging in the OPES program. Despite it taking Pam a year to complete the OPES program, her narration was void of any major difficulties that she experienced working through the program. One major struggle that ensued after she completed her cancer treatments and was feeling well again was her *husband's difficulty in letting go of his role as caregiver*. Pam did not discuss this challenge in the context of the program, but according

to her timeline, this was likely an issue during her participation. In addition, there were *some aspects of the program that Pam did not find helpful* – such as some of the *theoretical components* and certain aspects of the *module on erotic aids*. She also commented on the *significant amount of homework* required throughout the program and the unfortunate *lack of personal feedback*. In addition, *a significant misunderstanding* was revealed concerning her perception of being a research participant versus a self-help program participant.

One part of Pam's cancer experience that she felt was important for her to discuss was her *husband's difficulty in letting go of his role as caregiver*. She reflected, "He was in the caregiver role...which is a side of cancer we should talk about. Cause that can screw it up, screw up your sex life too." According to Pam, while her husband took his caregiving role really seriously and did a good job, she needed him to stop being her caretaker once she felt well and wanted to return to her normal "independent self." She felt her husband had come to think of her as his patient, when she wanted him to let it go and see her more as his partner and wife again. Pam described how this post-cancer dynamic impacted their intimate relationship as well as her sexual self-perceptions:

That was a struggle for us to get back to being equal partners. To get back to I'm a healthy woman now. Don't see me as sick. Don't see me as fragile. Don't see me as dying, I'm not!... So, when I hit my two-year mark...I was feeling better. I wanted to be on the forward-looking, leave this behind me, but he still needed that caregiver role somehow. Did it cross the bedroom? Probably. I can't give you anything specific, but it certainly was in our daily life, so it probably was an issue. In a relationship, in the bedroom, you want to be seen as vibrant, healthy, attractive... So, we worked on that. We

really did work. Probably he had to change more than I did, but I had to demand a little bit more.

With regards to the OPES program itself, Pam recalled that *the more theoretical portions of the program were of less interest* to her compared to the more practical components. One example was Module 2 that covered the four P's of sexual difficulties (predisposing, precipitating, perpetuating, and protective factors). Regarding her attitudes towards this module in particular, Pam said, "I had a pretty healthy, normal, average, guarded, childhood...then I met him at 14. So anything I knew, I knew nothing, we learned together. So, maybe that module didn't stick because there wasn't anything, unusual about us."

Pam also recounted that her and her husband's experiences with *the erotica recommendations in Module 11 (Erotic Aids) were not helpful* in increasing either of their levels of sexual arousal despite their attempts to engage in these activities. She said, "I didn't find a whole lot of help, in the erotica one. We had used erotica early in our relationship, often...but it didn't seem to do much for us anymore." She wondered if their age or choice of erotic material was to blame for their disinterest in this portion of the program. She recalled, "Gee, I tried half a dozen times to get going on that [book recommendation], and it was like, 'Naw, this just doesn't appeal to me.'" However, Pam claimed that she found the recent best seller, *50 Shades of Grey*, very appealing! Pam also described how *watching erotic videos* as part of this module *was also not helpful*:

It looks so technical and so forced. And the girls look so young... it wasn't a turn on! I was looking at them as human beings. I don't know if that's normal or not, but, I mean, we used to watch porno movies, and get turned on. We wouldn't have them on for a

minute! And we'd be doing it! But, this one, I think we watched for like 15 minutes and thought, "Oh, that poor girl"... Yeah, it wasn't working. And I guess that's pretty normal.

Pam also commented that she *found the homework exercises very time consuming*.

Considering the amount of time she said she put into responding to the homework exercises, she relayed: "It would have been nice to have a little confirmation, affirmation, or suggestion, follow-up. That would've been nice." She added, "I kind of felt like I was, filling in the blanks, to a void. It was empty." She continued to wonder whether or not her responses were useful to the research and asked if it was ever used for anything. As Pam reflected further on this particular aspect of OPES, she revealed that she found *the program lacked interpersonal connection*. In her words:

I didn't feel like it was personalized. It was very scripted...It was fine for me, but had someone look at my results, I don't know if anybody ever did look at what I was writing, or commenting on, or experienced... I never felt like there was any personal connection to what I was giving them. I never got anything back.

Pam recalled having felt like she "might have been one of a whole bunch" of other cancer survivors participating in the program – the lack of interpersonal communication resulted in her feeling uncertain whether her feedback mattered. She felt isolated, especially considering she was at her cabin "out in the middle of nowhere at the time when I was doing these."

As Pam discussed this limitation of the program, a *significant misunderstanding* revealed itself between what she thought she was achieving as a participant, and the purpose of the OPES program. As she reflected on her participation, Pam recalled thinking that she was doing the program in order to help other cancer survivors rather than approaching it as a self-help program intended to assist her with her own sexual difficulties. She commented:

Isn't that interesting. So it was offered to me, to help me. And I thought I was helping somebody else. Cause I thought that those answers to those questions or the feedback I was giving you, I thought that was going to be used somehow to help somebody else. Isn't that funny.

Although the OPES discussion board was intended to provide participants with a social support component to the program and an avenue to ask questions, Pam recalled that when she participated in the program the discussion board did not offer a lot of support either. She commented, "The only thing I remember from the discussion board was when the technology failed us. Someone would say something. This doesn't work!"

Motivations: What kept her going through the OPES program? Throughout her narration, Pam perceived several things as having had a positive impact on how she approached and worked through the OPES program. One theme was the *absence of significant physical or psychological problems* post-treatment that affected her sexual wellbeing. The supportive relationship dynamics in her marriage that enhanced her participation included a *long-term loving and supportive relationship* where *sexual and physical intimacy were highly valued*, and a *keenly interested husband*. Her motivation was also aided by her *desire to make her husband happy* and *wanting to help other cancer survivors*. Having *their family cabin* was also important as it provided a private and meaningful place for Pam to complete much of the OPES program.

Pam admitted that her participation in the OPES program was likely facilitated by the fact that she *had not suffered from any significant psychological distress or major physical impairments* as a result of her cancer treatments. She recalled that she recovered from her hysterectomy quite quickly and was in a good position for regaining her sexual wellbeing afterwards. She explained:

I mean, cancer or not... its not like I had a huge dysfunctional anything. Everything really did function quite well. I had some dryness and I had some low libido, but a healthy relationship with my husband – the stage was set, to have good sex. I never really had any – like I read about these women on that website, *Eyes on the Prize*, who have serious, like clitoral changes, or labia, or whatever, and I think, “Oh, man! They really have a struggle.” And this [program] probably would have really helped them... But we didn’t have anything hugely physically wrong with us. We were getting back into doing what we love to do anyway...

If anything, she said their sex life greatly improved after her surgery as it ameliorated the severe pain and bleeding that had prevented her from being sexually active for a long time beforehand. Several times, Pam reiterated how grateful she and her husband were that “everything worked” – that she was able to make her husband happy and vice versa. Pam did *not believe that cancer changed her sexuality*, and felt this likely influenced how she approached the OPES program:

I think if you had people that didn’t complete it, they probably had bigger issues than I did. Maybe. And if you had people that didn’t find it helpful, maybe they had bigger issues... I had emotional things to work through, but physically, I think it was just the menopause part of it.

A prominent theme throughout Pam’s story was her perception of *many supportive relationship dynamics in her marriage* that had a positive impact on her participating in, and completing, the OPES program. She credited her husband’s love and support as being the key to her successful outcome in her cancer journey. She said, “He’s a big part of my story... And that leads into sexuality, doesn’t it? I mean that’s what it’s all about. It comes naturally when the rest

of that is healthy.” From her perspective, she felt cancer actually brought them closer together: “It was that huddle that we had to do, it was something we did together. From a marriage point of view, from a partnership, it definitely brought us together.” Looking back to that time, she reflected on how *their sexuality had always been strong* and it endured cancer without really changing: “...even though it was in the intimate parts, I don’t think we let the cancer affect that part of our life.” Pam considered *sexual intimacy, or sexual intercourse, to be a very important part of her marriage*. In her words:

I think, in my opinion, sex is that glue. The intimacy is that glue that keeps you together. And, if we’re having regular sex, things are great. I mean, he’s happy! The next morning, you can see the smile on his face! Like, yeah, it’s just so important for men. Less important for women, I think. But for a man, he was just wearing that the whole daylong the next day...it’s so important.

Pam was motivated to nurture their sexual relationship by her *desire to make her husband happy*. Prior to the OPES program, she recalled, “I knew I wasn’t stepping it up in the desire part...and you want to make him happy. So you’re looking for ways to connect more often, or as often as he wants to.”

As well as sexual intercourse, Pam clarified that *intimacy was essential*. She described in detail the importance of physical intimacy in their marriage:

The cuddles. The spooning, the kisses, the hugs, just the closeness. I think the touch. It doesn’t have to be intercourse...it just has to be that closeness, and I think that’s what I mean by intimacy. He’s very affectionate, as I am, openly, in front of the kids. We’ll often hug, or kiss, or whatever and I think that’s the intimate part of it; that’s important. Because you can have all kind of issues, all kinds of ups and downs during your day, good things,

bad things. But if you're together intimately that way, it can kind of smooth out the rough edges. You see the person a little bit softer, a little bit more vulnerable, and well, maybe you're not so mad, maybe you're a little more understanding.

In reflecting on what kept her going through the OPES program, Pam recalled how *her husband was keenly interested in her participating* in the OPES program. Affectionately, she recalled, "he was always a really good sport." She laughed as she recounted conversations they had about her decision to do the program:

And of course, his reaction was, "Oh yes!!! And we'll do the test together!" I said, "There's going to be homework." He said, "I'm all in for the homework!" So, he'd say, "You had a new module! So, what's the homework this week?"

Pam explained that because *they were so comfortable and open with each other*, they were able to approach the OPES program as "a little bit of a game, as a little bit of a distraction, and we enjoyed what we could of it." Maintaining regular frequency of sexual intercourse was important for both of them, so Pam would not have to use the dilators to keep her vagina patent. She recalled with amusement how she and her husband would banter about having more intercourse as a means of vaginal rehabilitation:

I'd say, "You know, if we don't do it more often we are going to have to use those dilators"... I mean, just because of the relationship we have, it was always a good chuckle when, "Well, we have to do this because we have to keep open!" If you don't use it, you lose it... Sometimes we did it when we didn't always feel like we wanted to do it, but we knew that it was important to keep things from closing in.

Pam disclosed she and her husband spend about 6 months of the year at their lakeside cabin. *Their cabin was a place of refuge* during Pam's chemotherapy treatments; a place where

they “took care of themselves.” It also provided them with a private, romantic environment where they could attend to their sexual healing. This was where Pam recalled she and her husband completed much of the OPES program together (mainly in the off season when it was not busy with visitors):

It’s just the two of us. Everybody is gone from the lake. It’s lovely. And that was part of our healing as well. It’s always been our special place... and we’ve had sex on the boat, each of the bays, and certain beaches that we go to around, and sexually, it’s been a nice place because it’s been so private and alone.

Aside from their relationship dynamics that reinforced Pam’s commitment to completing the OPES program, her expressed *desire to help others* (i.e., other cancer survivors) was another important motivating factor both in initially participating in, and completing, the program. She explained that this was something that her son, who was in medical school at the time of her cancer treatment, inspired her to do. She explained:

...There’s people out there who need people like me, to study, to test things, and what not... [my son] kind of inspired me to give of myself. And I’m an open person anyways. So when I got approached to do this study, I thought, “Yeah! That’s some way I can give back, and open up.” And like I said, we had a healthy sex life anyway, so there might be something there to learn.

Benefits experienced from participating in the OPES program. As Pam narrated her experiences with the OPES program, she described four prominent benefits she derived from participating in the program – her *learning about women’s sexual desire* as part of the sexual response cycle, participating in the *partnered sensate focus exercises*, *encouragement to use a vibrator*, and *overall enjoyment in working through the program*.

The most important benefit that Pam acknowledged gaining from the OPES program was *learning about “responsive sexual desire.”* After her treatment completion and ensuing menopause, Pam noticed she was not in the mood for sex as often as she had been pre-surgery. She recalled that when her husband would approach her for sex and she wasn’t in the mood she would “shut him down too quick.” However, what she took away from learning about responsive desire was that even if she didn’t initially feel like having sex, if she gave her husband the “opportunity to change her mind” then this would often “turn into great sex!” She explained how she found this module helpful:

If you give him a chance, it can often be really good...it was like just relax and let it happen, give him the time and the attention, and the guidance. And sure enough it worked. And I still use that to this day. When he’s in the mood, and I may not be, I kind of prepare myself, Okay, well let’s just give him the time. And it works!

This “extremely helpful” and “really encouraging” part of the program, Pam claimed, was “probably the best thing I learned from it and still use to this day.”

It was evident from Pam’s narration that she and her husband really enjoyed doing the OPES program. She disclosed how she and her husband especially had *fun with the homework exercises*: “Like I said, my husband was rubbing his hands, thinking, ‘Oh Boy! We get homework tonight!’... And we joked about it during the day that we were going to have some homework to do!” *The sensate-focus exercises were particularly enjoyable*, as she remembered: “I think one of the modules that we had fun with was the touching!... That was a fun one.” She explained what was fun about these exercises: “just the anticipation. I don’t think we would’ve gotten a passing mark, cause we clearly wouldn’t stop when we were asked to. But we did have some fun with that one.” It appeared this exercise was beneficial in that it *added something new*

to their usual sexual repertoire that they had not previously explored. In her words, “And, you know, we’ve never taken any courses or any instruction that way. I mean that was just fun to kind of explore some directions that way, right, that we hadn’t really done before.”

Since participating in the OPES program, Pam recounted that she and her husband were *using a vibrator* more often than they used to. Pam articulated how using this device was *helpful in increasing her own arousal and pleasure* during sexual activity:

That’s great for me. I really like that. He says its good for him too... I prefer it, well, I don’t say I prefer it – I like to have it with him, and that is good for me. Cause I get an orgasm every single time I use the vibrator, but I don’t every single time with his foreplay. We might try to start that way, and then we go and use the vibrator and then that takes me to where I want to be.

In summary, Pam thought overall the OPES program was good. She said, “I think there was more good than not. It was worth my time.” She added that it was really easy to access, even when they used a slow Internet line. She felt it was important to use the technology available today to help people that would otherwise not be able to access this sort of program. In her words:

I think what their aim is a good one. I don’t think they should give it up. I don’t know what kind of results they had, but I think it was worthwhile. Because you’re reaching people who may not have availability to that kind of support.

Where she is now after participating in OPES. When Pam reflected on her experiences of the OPES program, the negative consequences of radiation treatment on her sexuality was largely absent from her narrative. However, it was clear as we began our interview that Pam continued to have an emotionally difficult time talking about the impact this treatment had on her

life. Pam considered radiation treatment “the most difficult to go through,” and relayed a common expression known among cancer survivors: “Radiation is the gift that keeps on giving.”

She tearfully described what this meant to her:

Every year, 6 months, another symptom comes up, another issue and it goes back to the radiation. So, yeah, that was a tough swallow on that one... it’s left me with a lot of sexual issues that are related to the radiation. And then the bowel issues are really uncomfortable, constant diarrhea... It’s all about the radiation damage. I think that’s what has been the biggest hurdle, after the cancer experience, was the radiation outcome.

Pam noticed that over the past six months, *long-term damage from the radiation* was creating more pronounced “scar tissue build up” and “skin changes” resulting in the further shortening of her vagina. As a result, *sexual intercourse was becoming more uncomfortable*. She was managing these symptoms by using lubricants, increasing foreplay, and relaxation. Pam also mentioned she was now having *a lot of incontinence and bowel movement issues*. However, she rationalized that these difficulties were “all perhaps for good reason”; the radiation might have been what cured her and saved her life. Pam’s willingness to accept these otherwise unfavourable consequences of the radiation therapy were revealed in the following words:

I just have to keep holding onto maybe that’s what killed all the cancer cells. Maybe that’s why I am here now, is because we were so aggressive with the radiation ... It’s stuff that I can manage, nothing that I can’t work through and find a way around. So yeah, I’ll take it... And happy to do so. Happy to be here.

When reflecting on her current sexual wellbeing, Pam commented that her level of sexual desire had not really improved since the OPES program. She noticed that her husband’s sexual interest also seemed to be declining. This did not seem to disturb Pam as she considered these

changes were likely a natural part of their aging process:

Libido wise, that hasn't changed. Like it's still not there. But I think that's pretty normal.

And then I find he's not as interested either now. His libido seems to be, my husband's 62, so I think that's pretty normal too. When they get a little older.

On the other hand, Pam commented that they had both lost a significant amount of weight over the past year and that has "been good in the bedroom" – giving her husband a little more vigour, helping her feel better about her naked self, and increasing the variety of sexual positions they could try. Pam felt that *her and her husband were "a pretty good match" when it came to libido*. She described how their sexual life is now:

I don't have any wild expectations. It's all good, when we do it. We probably just don't do it as often as we used to. Which is pretty normal I think. When we were young...we did it a lot. As soon as we saw each other, couldn't wait for that part of it to happen. But now it's a little more planned, maybe a little more – a little less passion, and a little more enjoyment, gentle enjoyment.

Advice on how the OPES program might have better met her needs. According to Pam, one significant shortcoming of the OPES program was the lack of interpersonal support and feedback. When reflecting on what advice she would have for the program, she said, "I guess what the next logical step would be is a *personal conversation with someone*. That wasn't offered, I don't think." Considering the nature of the program material, Pam wondered, "...isn't that the best, to have a *personal one-on-one with a counsellor* about this stuff?" She believed that a phone call or some sort of communication initiated by the program would actually take the OPES program one step further. She also thought it would have been helpful if there had been a *response to what participants were writing online* for each modules' homework exercises,

personal reactions to activities, and feedback commentaries, such as a “next step” or a “referral.” Considering the time and effort Pam recalled putting into responding to the modules’ homework exercises, she would have liked to receive some sort of confirmation that “someone on the other end has listened and read what you wrote, because you took the time to write it.” She added that participants could be asked such things as: “So you experienced this... well this might be some information you’re interested in, or have you tried this...?” Pam believed that type of focused feedback would have made her experience of the OPES program “much more valuable.”

An example Pam provided was concerning Module 11’s recommended erotic novels books and film clips that did not work for her. She said when she had responded online to these homework exercises as “not doing it for her,” someone could have responded to her with: “Well try this one, this is a better book” or “here’s another resource.” It frustrated Pam that there were no responses to her comments when things in the program were not working for her. She has the following to say about this particular shortcoming of the OPES program:

That’s an example of where, if someone had been reading that and spending a little bit more time, they could’ve given some *real* help. So when you [the program] provide those 12 modules, you’re thinking, “Here’s 12 areas that we can help you in.” But when I [the participant] give you some information, there’s probably a little bit more you can help with.

Natasha’s narrative. Natasha is an active 62-year-old retired post-secondary teacher living in the lower mainland of BC with her husband of 33 years. They have an adult son and daughter. At the age of 54, Natasha was diagnosed with Stage 1 breast cancer for which she received a lumpectomy followed by a month of radiation. As the tumour was estrogen-positive, she participated in a clinical trial that involved taking Arimidex (a breast cancer treatment that

reduces estrogen in postmenopausal women) as a preventative measure for an additional 5 years. About 4 years after her lumpectomy, Natasha participated in the OPES program which took her approximately 24 weeks to complete. Three years after she completed the program modules, Natasha participated in this interview. Approximately a month prior to her scheduled 6-month OPES follow-up questionnaire, Natasha received extensive surgery to repair severe pelvic floor prolapse that developed during the time she was on Arimidex, as well as a total hysterectomy.

Relevant background information. Natasha was one of three women with breast cancer who were included in the OPES program. She was the only breast cancer survivor who completed the program. As Natasha narrated her story, it became evident that there were two significant parts to her cancer story that were important for her to share as she felt they impacted how she perceived the OPES program. These related to her pre- and post- OPES program experiences, and are discussed in some detail below.

Pre-OPES program experiences. Natasha attributed most of her “sexual issues” as originating from having diligently taken Arimidex daily for 5 years. She discussed the following side effects that impacted her sexual wellbeing before she participated in the OPES program:

I experienced, basically by eliminating the estrogen, besides helping my body to fall apart faster, [Arimidex] had also eliminated my sex drive...and of course, with no estrogen there's no lubrication, no anything...our sex life had really dipped, to put it mildly, over the course of the five years.

Natasha felt that taking this medication, “basically put me in a kind of nonsexual position for quite awhile.” She added, “everything was atrophying because I hadn't had sex for so long, or we'd try and it was just too painful and then, of course my husband didn't want to hurt me.” This was a difficult change for Natasha because she felt like she was “missing a large part of her life.”

She described how Arimidex, as well as menopause, and the ensuing burning from vaginal dryness and lack of lubrication, had a profound impact on her and her husband's sexual lives:

The pain issue turned me so much off sex and intercourse...the interest wasn't there... and then once you put it on the back burner for so long, it's just easier to stay there. So now you say, "Okay we can't have sexual intercourse, so lets just do this instead." Well, I wasn't all that interested. And then sometimes it made me sad because my husband wanted to do things, and I'd said, "Well, so you can still have that but I can't have that." So you feel selfish in some cases.

When she discovered an advertisement for the OPES study on a bulletin board at the BC Cancer Clinic it resonated with her struggles, and she recalled her reaction: "I wanted the study...I wanted that information. I wanted to participate." She said the OPES study came along at a good time for her because, "basically... [I] was not really thinking of [sex] as much as I missed it." She expressed how grateful she was that the study team agreed she could participate despite not having had gynaecological or colorectal cancer.

Post-OPES experiences. Approximately 3 months after completing the OPES modules, Natasha finished taking Arimidex. By the end of this treatment, Natasha had developed such severe pelvic floor and uterine prolapse that she had to have anterior and posterior surgical pelvic repair and bladder repair, as well as a total hysterectomy. At the very beginning of our interview, she explained that the OPES program has been helpful as a resource after her pelvic surgery because it is even more relevant to her now after having had "gynaecological surgery." This surgery was quite traumatic for her as she recalled: "Emotionally it really took me a lot back to cancer." While her sexual life after the OPES program seemed to have been improving, the post-surgical outcomes she experienced resulted in another significant setback in Natasha's sexual

recovery. In her words: “There wasn’t a gap where I wasn’t on medication, and I was just starting to think that I was really enjoying things again, and WHAM! Within 2 months, I had surgery, and then down a *whole* different path.” Her recovery period was extremely long and intensely painful. She recalled having intercourse had become virtually impossible due to scar tissue. After many medical investigations, Natasha learned she had developed chronic interstitial cystitis due to damage to her bladder lining from 8-months of untreated post-surgical infections. She recalled wondering, “Will I ever get my life back again?” Several months before our interview, she sought treatment for her genital pain from a pelvic floor physiotherapist. She credited the work she did with her physiotherapist as “really having turned things around” in that intercourse was now possible, although she admitted was still not very frequent.

Challenges faced when engaging in the OPES program. In Natasha’s narration of her experiences with the OPES program, she faced the challenges of *paying attention to her sexuality despite how painful this was* and *addressing her sexual difficulties head on versus avoiding them*. The most prominent challenges she discussed that were specifically related to the OPES program were the *significant time commitment* that was involved and the *intensity of doing the program in only a 12-week period*. She admitted this *required a lot of self-discipline*, especially when program *technical problems* added unanticipated hindrances.

When Natasha signed up for the OPES program, the physical and emotional ramifications of having been on anti-estrogen medication for five years had resulted in a loss of her sexual wellbeing. “When we were younger, we were quite sexually active, we had a healthy sex life...that was *before* cancer.” Recommencing sexual activity therefore meant *facing the challenges she had been previously avoiding*. Natasha recalled:

[Sex] just caused so much angst and so much emotional pain and later, physical pain...it

was just easier to put it aside. I'm sure it hasn't been fair to my husband, but he's been very understanding. But that's the only way I could deal with it...I used to think, and most people I guess do, think of sexual as pleasure. And through my experiences, became more physical pain first of all, and then emotional pain as well by not having that. So as much as I missed it, I just was too worried about the pain, and well I'll just avoid it and then not have to worry...

Despite these emotional, relational, and physical challenges, as Natasha reflected back on her participation she identified the *intensity of the time commitment* was as the most onerous aspect of the program. She felt she, and possibly the program coordinators, *underestimated the amount of work* that would be involved in participating, and recalled, "It did take quite a bit of time, a definite commitment to it." Given the time commitment and intensity of the program Natasha guessed that many of the participants who started the program likely would not have finished it. She recalled that the program modules: contained a lot of detailed information, she had to re-listen to the audio clips many times, answer online questions, do homework exercises, take time to reflect on the material, and talk with her partner about relevant topics or coordinate their busy schedules to work on the partnered activities at a time when they were both rested. While she set an hour a week aside for the program, she found it took more like 3 or 4 hours. Natasha remembered the pressure of working on the program in order to make the weekly deadlines and recalled *feeling overwhelmed at times*. She revealed, "I thought they needed it by a certain deadline because there was a cut off... I thought that it was a time line we had to meet." She said she didn't know how she would have accomplished this program if she had been working fulltime:

I was glad I was retired. Because I thought if I wasn't...it would have been a different

story. And in spite of being retired, I have an active life and sometimes I had a hard time fitting it in...and I am not working anymore!

On the other hand, Natasha explained how she understood this was likely the nature of participating in research and the responsibility of being a research participant. She reflected, “But it’s a research study. I realize that, so that’s the nature of the beast. They need the detail. They want the depth, the breadth...They were looking for everything.”.

When comparing the OPES program to other cancer survivor support groups she attended, Natasha felt the regular in-person meetings provided a certain degree of social accountability that would encourage members to complete their homework. Because this was missing from the OPES program, Natasha felt completing the program was “harder because you *had to have some kind of self-discipline*.” Natasha added that she recalled experiencing some “*technological problems along the way*” with the online program that also delayed her progress. For example, she recalled times that the program didn’t recognize when she had finished some modules, and prevented her from continuing onto the next module.

Motivations: What kept her going through the OPES program? Despite the program intensity, Natasha was highly motivated to complete the OPES program. From her perspective there were several things that facilitated her continued participation – her *supportive and close relationship with her husband*, as well as *his interest in the OPES program*; her *belief that sex was an important part of life*; and her *persistence towards recapturing her sexual wellbeing*, while maintaining *hope that things will get better with her efforts*. In addition, *being retired*; her *willingness to experiment with new ideas*, and *being a responsible person* all contributed to her success. It was also evident that she participated because she *wanted to help others*.

Natasha described her *marriage as being very close and intimate*, having “shared many of

the ups and downs of life...we're soul mates for each other...we're very close friends besides being husband and wife." Natasha expressed her gratitude for the support he provided since she was diagnosed with cancer, "I value that with my husband. We did get closer cause there were lot of times where I was very upset ... very emotional time. Yet I had the support. Couldn't imagine if I didn't have that kind of support!" Having a satisfying sexual life together was a shared common interest, although Natasha recounted how they were struggling to regain this. In the following passage she shared how patient and understanding she felt her husband had been:

I used to have a very high sex drive, so it was the flip side, completely, to what I am now and that was a big adjustment for him. He's adjusted as life has gone on, but I think he still has quite a high sex drive. I'm sure it's been very hard on him. We've talked about that but he said he wants me to be healthy, number one, to be healthy in all aspects. So he said, "It will come, be patient. We'll get there together."

Having her husband's unwavering support, cooperation, and their being able to "talk about anything" clearly facilitated her progress. For example, "If I would have frustrations...or I really need you to do this because I got to go back to the study...and just to make the time. So, we'd make a date...to talk about it." Despite not having sexual intercourse, Natasha said they continued to maintain their physical intimacy, "We've always talked, we've always touched, I don't know how many times a week. Our son, he even says, 'Oh, hey you two smooching in the kitchen!'...We've always been like that."

Even though Natasha considered herself "as more outgoing" than her husband, she credited him as being the more sexually adventurous one, "sexually he's the one that's more willing to try different things than I am." However, rather than being a source of contention, Natasha appeared to be receptive to his propositions and, in fact, took them as a challenge she

wished to address. She shared the following scenario that was an exemplar of this relationship dynamic:

I remember my husband said something like, I was kinda “*Vanilla!?!*” I thought I was like chocolate swirl, or something like that. “*Vanilla!?!*” I was a little offended. He said, ‘Well, a little conservative.’ And I like to think of myself as being kind of open. I think I’m quite liberal and open-minded...but, sexually I thought, ‘Oh, really!?! I’m vanilla?’... Well, maybe I should spice things up a little bit, so it’s not too vanilla! And so we made a commitment to... And it feels good.

Another example of how she was *willing to go outside of her initial comfort zone* was her openness to incorporate more erotic aids into their sexual relationship. She recalled her experience of going to a sex store for the first time in over thirty years:

I guess I found myself a little embarrassed because we hadn’t done that kinda shopping for a long, long time. I thought, “Oh well, my goodness. I’m 62 years old, I should be able to do this and not be embarrassed!” We just looked around and bought things and started trying things.

Natasha explained she was very *motivated to try whatever she could to recover a satisfying sex life*. Her determination to address her sexual problems was what lead to her request to participate in the OPES program. She also sought out and read many books to find what might help. She said she *maintained her “hope that it’s going to get better.”* Natasha’s *persistence in meeting her goals* was palpable throughout her story and appeared to help her deal with challenges that arose when participating in the program. For example, the following passage demonstrated her tenacity: “Say this is not satisfying. What can we do?... We have to try different things. Say that didn’t work, that position hurt, or that didn’t go...Okay, we won’t do

that, let's do something else instead, or just give little breaks..." Natasha came to the realization that despite how much they may have wanted their sexual activity to still be spontaneous, since her cancer treatment and surgery this was no longer possible. Rather, she explained, "I'll save the energy and I'll make sure the night before, I'm putting in the estrogen to get things geared up... You do what you have to do, what you can anyway. And then hope it will get better."

As well as her tenacity, Natasha's sense of responsibility clearly contributed to her successful completion of the OPES program – she was *dedicated to following through on her commitments*. Because she was allowed to participate in the study despite not meeting the criteria of having gynaecological or colorectal cancer, she was particularly grateful and even more committed to completed the program: "I signed up, and I was very pleased that they let me in, so I was going to honour that... I'm going to commit... I knew that I was going to finish it." Natasha also pointed out more than once that *being retired* was an important contributing factor to her completing the program. She said, "I didn't have the obligations of work, so I had time to do this as well."

Natasha was also motivated to participate in, and complete the OPES program, including our interview, for *altruistic reasons*. In discussing some of the other cancer-related studies and support groups that she had participated in prior to the OPES program, she explained they really taught her, "the power of the need to be listened to and the power of having someone listen to you." After all her cancer-related experiences she found this validation was so important to her that she was inspired to find ways of offering this to others, such as volunteering with outreach and participating in research projects such as the OPES study. She explained, "I've got to give back, basically, see if I can give back in this way....and hopefully contribute to something, like cures." Importantly, Natasha added that participating in the OPES study was a way she felt she

could represent and advocate for cancer survivors with sexual difficulties outside of gynaecological and colorectal cancer. In her words,

[I'm] kinda representing those who weren't specifically in the parameters of the study, but with the hope that you would expand [the OPES program] in the future for breast cancer or for other issues...like for people with lung cancer, or for brain cancer, other issues that would affect their sexuality as well.

Benefits experienced from participating in the OPES program. Natasha felt she received many benefits from participating in the OPES program. One prominent theme was bringing *sex back to the forefront of her life and marriage* – rekindling sexual intimacy between her and her husband. The program did this through encouraging her to *re-evaluate the importance sex had in her life*, inviting her to *learn more about her sexual self after cancer* and encouraging her to *try new erotic activities*. The sensate-focused exercises and the module on erotic aids were particularly beneficial. Through participating in the program, she felt *the level of openness shared between her and her husband increased* as they learned more about each other's sexual self-perceptions. In addition, despite the program's intensity, *the program's structured helped her maintain focus*, and served as *a helpful resource*.

The first module of the OPES program set the foundation for Natasha's positive experience with the program. When she was asked to rank how important various things were in her life, including "a rewarding sex life," she recalled thinking, "maybe I haven't been giving [sex] enough importance in my life for so long... so just to *bring [sex] to the forefront and give it more time and attention*." When contemplating on the program's positive impact of getting her to think about things she had not even thought about before, she remarked, "We're supposed to know ourselves better by this age, right?!?" She said the OPES program provided her with

opportunities for a lot of self-reflection and helped her “*look at things from a different perspective.*”

It kind of motivated, not motivated...but it *triggered* things...It was good...you had to think about that, that you honestly had to be honest with yourself, and to be honest with the study... And so you had to kinda re-evaluate. So that was useful.

Bringing her attention back to the fact that sexuality was indeed important for her and her marriage was a significant benefit Natasha, and her husband, experienced from participating. Natasha recalled how she and her husband found the partnered exercises particularly helpful, not only in *reconnecting them physically* but also in *opening new lines of communication*. She recalled how valuable the sensate-focused exercise was:

We were trying to make our comeback so to speak, sexually, just to do the nonsexual, just do the light massage, things like that, and just talking ... We've known each other for many years, but we've never talked about this before, or haven't for a long time.

She added that this activity was particularly useful because the “guidelines” instructed couples to avoid sexual intercourse. This encouraged her to control how she wanted this exercise to unfold and as a result, it *provided them with a new experience* where they learned what type of touching each of them found to be pleasurable. In her words:

I would go back and say [to him], ‘*We’re trying different things!*’ like just the sense of touch, just finding out where, what parts of our bodies were more sensitive...without progressing. Cause men tend to want to continue on, [touching] is a precursor, a step, towards sex. ‘No, that’s not the goal!’

When reflecting on the module on erotic aids, Natasha recalled *learning new things about her husband*. She learned that “fantasy” was much more important to him than it had ever been for

her. While she recounted that she didn't really use fantasy, this got her thinking back to when they were young and would make love outdoors, and she recalled thinking that she "would like to do that again." She explained how the *novelty of discovering new things about each other was helpful*, even if it caused some discomfort:

If it raised an issue that was stressful...then we did talk about it. Yeah, and it did. I think I know my husband very well after all these years, but sometimes, "Oh, I never asked you that before!" or "Oh, what about such and such?" "Oh, that's interesting!" And then he'd say, "So what about you?"... So, that was good."

Natasha also learned that her husband was very interested in incorporating sexual aids/ toys into their sexual repertoire. She admitted that she "didn't know that much about him." She amusedly recounted her husband's enthusiasm about the module on erotic aids: "'Oh really! That's a part of your homework?!?' I said, 'Oh yes, that's part of the homework!' [he replied], 'Oh yes, lets go shopping!'"

Natasha acknowledged that a positive consequence of participating in the program was that she was more *open towards her husband's invitations* rather than making excuses such as, "I'm too tired," "I've got a headache!," or "I've got too many activities going this week." She also found herself wanting to challenge his perception of her as being "just plain old vanilla." In fact, she believed that her participation brought with it a *new level of openness* between them, and *encouraged her to try new erotic activities*. The module on erotic aids was also beneficial because it suggested various stores in the lower mainland where she and her husband could go shopping for a variety of sex toys, "we went to a shop and bought some new things...to try them. And...Yeah! Well he was happy. He was relieved because I...started to kinda be more interested as well."

Despite the intensity of the program and other challenges she faced, Natasha had positive things to say about the structure and format of the program. For example, she commented that having a deadline to finish each module, and covering one topic per week, *helped keep her focused on one aspect of her sexuality at a time*. She said it, “took you though the whole spectrum” of topics important to her sexual recovery, and added that it guided her to places she may not have gone on her own (i.e., experimenting with sexual aids). She also found the online format was helpful because, she could *do it at her own pace*. For example, she revisited modules more than once, returned to sections after taking some time to reflect on what was brought up, or broke modules into smaller, more manageable pieces. Doing this program online, where she knew her responses and feedback were being recorded, she felt the *feedback she was providing was being listened to*. She also said she appreciated the psychoeducational aspects of the program and how detailed the modules were. She said that although the program was intense, she felt *a sense of completion* having done it.

Natasha referred to the OPES program as having served as a conduit towards furthering her sexual healing. She felt the program was like a *stepping-stone* that provided *a segue to greater openness and communication* between her and her husband. The program continued to be a *very useful resource* that she would refer back to from time to time and follow-up on the various *recommendations and resources*, or do further research at the library on topics that were presented. Sometimes she would find herself saying, “Oh, remember such and such.” She reflected, “I can see myself even now, going back to certain things and stuff that was helpful...I’m very glad I did.”

Where she is now after participating in OPES. Natasha believes that her and her husband’s sex life has improved through the OPES program. However, the long-term effects

from the pelvic surgery she had shortly afterwards, exacerbated the physiological difficulties she was having prior to the program and continue to have a profoundly negative effect on her sexual wellbeing. What was especially important for Natasha to share was how integral the *pelvic floor physiotherapy* she started several months before our interview had been in reducing her genital pain. She explained that this treatment helped her to finally get to a place where she could even attempt sexual intercourse again. She recounted that some of her doctors did not even know that pelvic floor physiotherapists existed, which she felt was unfortunate given how helpful she found this treatment. She said, “for all this long course, I'm finally getting help that worked towards having some kind of sex life come back,” and added, “*it's [her sex life] still not very active but at least it's not as painful.*”

Despite all the challenges, Natasha clearly *continues to demonstrate determination to heal her sexual self*. Compared to how she remembered having put her sex life on the back burner prior to her participation in the program, this no longer seemed to be the case. Upon reflecting back on all the repercussions resulting from her cancer treatment, she expressed regret over the decisions that had been made without her awareness of the potential risks with which she was now suffering. She said, “I never thought that it would come to that. Very surprising... when you're young you think it's going to go on forever – how I used to be, and so it is sad.” She expressed a real sense of loss, “I've kinda lost from 54 to 62, I've lost those years and in many ways...I can't get them back.” However, she *continues to have hope that things will improve*:

I'm tired of living like this. And so that's why I said step by step, that's why I was so motivated to find the right medical help, and to find pelvic physio, and everything like that. To say well getting closer is getting closer...having some kind of so-called normalcy... And part of normal adult life is having a sex life... being able to have a sex

life with your partner... and I didn't have it for so long. So, I'm really motivated to get it back.

Natasha looks forward to “a sexual life that’s more pleasure than pain,” so much so that despite her ongoing concerns about using this product, she said she finally heeded her doctor’s recommendations (and safety assurance) and started using Vagifem (a prescription vaginal estrogen tablet) to help treat her atrophy. She hopes that with all the skills she had learned (i.e., from OPES and physiotherapy), and her new regime, a combination of Replens (a vaginal moisturizer), Vagifem, and Premarin cream that she will continue to notice improvements. She relayed her enthusiasm towards the next steps she and her husband have planned: “We just bought some new toys, and some new things, and this lubricant, trying to revitalize our sex life. I'm not the same as I used to be, but still...we have some good years left ahead.”

Advice on how the OPES program might have better met her needs. According to Natasha, incorporating more *interpersonal connection or support* and providing a *longer time period within which to complete the 12 modules* were two ways she believed would have helped her get more from the OPES program.

Natasha recounted that participating in therapeutic groups for women with cancer could bring up a lot of emotion and having immediate support was important when topics became difficult. Receiving therapeutic support was a critical component in the in-person support groups she participated in prior to OPES: “we could have help on the spot. That was very helpful. Then by the time you went home you were helped, you dealt with something, you could still think about it later...but there was support right on the spot.” She felt the OPES *program lacked sufficient peer support or interpersonal connection*:

I did [OPES] on my own, but if there had been someone else I knew, who would have

benefitted from this personally, I would have encouraged them to participate in the study as well. And I would have liked to have had that immediate feedback from someone else, to be able to compare...I wasn't talking to anybody else, except my husband, basically. She suggested the developers of OPES think about implementing something like this, such as having the program *facilitator or a therapist available for immediate feedback*. She would have also been interested in *peer support* such as being connected with another participant, or going to "a feedback group" where she could meet with other participants face-to-face. Natasha did not find that the online discussion board offered her the peer support that she had hoped for. She recalled that the few times she visited the discussion board, there were not a lot of posts from others, even though she recalled having made the occasional post herself. The main reason she said she did not participate more fully in the discussion boards was because she had already spent so much time working on the program homework exercises.

Finally, Natasha was not aware that there was some flexibility in the timelines of when each module could be completed, and so she worked hard and felt pressured to meet each weekly module deadline. In reflecting back on her experience of the program, she believed that *having more time to complete the 12 modules would have been very helpful* and beneficial for her. "If I had more time I probably could've done more with it."

Maggie's narrative. Maggie is a 64-year-old retired teacher living in the interior of BC. She and her male partner recommenced their committed relationship 7 years ago after a gap of several years. He resides in the lower mainland. She has no children. At the age of 58, Maggie was diagnosed with uterine cancer and received a total abdominal hysterectomy with bilateral salpingo-oophorectomy and adjuvant radiation to her pelvis plus brachytherapy. Due to radiation damage, her bowels shut down a few years later requiring surgical removal of 3 to 4 feet of her

bowel, and a temporary ileostomy for a ten-month period. Approximately 6 months after receiving the ileostomy (4.5 years after her hysterectomy), Maggie participated in the OPES program during which time she had her ileostomy reversed. It took her approximately 40 weeks to complete the OPES program and our interview took place about 14 months following her completion of the program.

Relevant background information. Maggie discussed having had a very satisfying sexual life before cancer. Very early on in our interview, she explained how sexual desire had been a formative part of her relationship with her partner: “One of the most important aspects to our relationship, initially, from my point of view, I think from his too, was our sexual attraction. Pheromones on fire! I saw this man and, Oh my God! I pick you!” She recalled amusedly that the only problem she had with sex was, “it made me late for work... I couldn’t keep my hands off him and it was reciprocal.” Their relationship, she said, “took its course very quickly, because we were so sexually attracted to each other.”

According to Maggie’s story, this rewarding aspect of her sexual life was dramatically altered by the cancer treatments she received. Her hysterectomy shortened her vagina by 3 centimeters. The damage from the radiation was profound and ongoing – she suffered from atrophy of her ureter and vagina (despite following the doctor’s recommendation to use dilators for vaginal rehabilitation). Damage to her bowels, surgery, and a temporary ileostomy resulted in irritable bowel syndrome (IBS). In reflecting on the time she had the ileostomy, she said, “I’ve got this thing attached to my body, that hurts, that herniates, that gets infected, that does all this stuff.” She recalled, “it complicates your life – socially, travelling, sometimes I just shut myself [away].” At one point, Maggie remembered feeling terrified when she started evacuating feces from a fistula that had developed in her vagina and she could not even bear to have visitors. She

relayed how she had to fight to get validation and the proper pain medication from her doctor. Having an ileostomy, Maggie explained, “doesn’t make you want to get cuddly, and canoodle” so all sexual activity ceased.

Maggie discussed how supportive her partner was during this difficult period of her life, “he was with me all through my cancer treatment, and continues to be to this day.” He would fly over and stay with her four days of every week throughout her cancer treatments. In the following passage, Maggie described how caring and attentive he was:

It was gratifying because he always pushed the envelope. The time that he was here, he was here a lot, he would ask me that question a dozen times a day. How are you feeling?...And when I complained about my frustration with the whole thing, he’d say, “I think you are doing a great job!” It was like somebody was in the wings coaching him, but I knew that this was just coming from his heart.

Maggie said she felt blessed to have this level of emotional support and exclaimed, “I call him my angel!” Early in our interview, she said it was easy for her to answer the OPES question about the most important and valuable aspects of their relationship:

We have always had trust even though his work has taken him away from me and mine from him. That hasn’t changed...to this day. Honesty...because I find that we protect each other’s feelings.

Although Maggie was grateful for their emotional connection and ability to talk about the impact the ileostomy had on their intimate life, it was clear that she continued to grieve the loss of her pre-cancer sexual life and self, and the intimacy, spontaneity, and excitement that she and her partner had previously shared. Maggie wondered aloud, “Where did that go?”, and confessed that nothing her partner did to support her, seemed to make up for the losses she experienced

following her cancer diagnosis and treatments:

And no amount of compassion...or going overboard with sympathy, and the hearts and flowers kinda thing, could make up for that. I mean it was beautiful and wonderful, and I definitely was blessed and felt blessed, appreciated being blessed, but the rest of my body from here down was dead!

As Maggie narrated her experiences with the OPES program, other extenuating life circumstances that occurred in close proximity to the time she participated in the program were revealed that likely impacted her participation in the program. For example, Maggie's mother, with whom she had a very distressing relationship, died only a couple months before she had her bowel surgery and ileostomy. Maggie recounted that these coinciding life-altering events had a significant impact on her wellbeing, and she said she fell into a depression. She discussed how her depression led her to entering psychotherapy which coincided with her participation in the program. Her ileostomy reversal also occurred approximately 6 months into her participation in the OPES program and required several weeks of recovery. Throughout her narration, Maggie also briefly touched on her ongoing struggles with low self-confidence and self-worth, as well as body image difficulties, stemming from a lifetime of receiving her mother's constant criticisms, and having had a "horrendous childhood."

Challenges faced when engaging in the OPES program. As Maggie narrated her experiences with the OPES program, she recounted facing numerous challenges. The most defining circumstance was the *complete cessation of sexual activity following her ileostomy* and the *physical separation* between her and her partner that ensued. Her partner's lack of availability due to their *geographical distance* further complicated her progress. Other factors including *lack of libido, vaginal atrophy and pain, partner's penis size, genitally-focused sexual*

activity, and difficulty in communicating her sexual preferences. These factors all intersected in a way that resulted in the program being *overwhelming* for Maggie, and in her needing to set the program aside for periods of time. Maggie was also highly aggravated by certain *OPES module questions* which she felt *lacked sensitivity to participants' lived experiences*.

The *complete cessation of sexual activity* following Maggie's ileostomy coincided with a *physical distance that developed* between her and her partner. She discussed how her ileostomy impacted the physical intimacy that had previously been such an important part of their relationship:

We have gone for a long time...since my ileostomy, which was in 2012, we put sex aside all together. We were counselled about the effects of what ileostomy might do to our sex life, but Jon didn't want to put me under any pressure, so we just left it aside, without focusing on intercourse, or making each other feel better or anything. Having the ileostomy bag attached to my body, needing to empty it every 20 to 25 minutes, we talked about that a lot and I felt that he just let me be. He was there to support me, to talk to me about things that I was worried about, to let me get my frustrations and anger and embarrassment out, but he put no pressure on me sexually. And at that time, I had no interest in sex. Not even fondling. Not any precursors to sexual involvement...We cuddled. We kissed. In bed, we did not. It just wasn't viable.

Maggie talked about the "3 feet of space" that had grown between them in her king size bed. In reflecting on what impact these changes in their relationship had on her, she said, "from my point of view, it was extremely frustrating. I often felt angry. I dove into depression. I was angry at Jon when I shouldn't have been."

Maggie's progress through the partner-involved sections of the OPES program was

further impeded by the *geographical distance* of them living in different cities. During her participation in the program, Maggie eventually requested to skip module 7 (Relationship Satisfaction & Communication), and return to it later, because her partner was not available. She also confessed that even though they had discussed the partner-sensate focus exercises over the phone, they never actually tried this.

Maggie suffered from *vaginal atrophy* that caused extreme *discomfort and pain with penetration* (including when she attempted to use her vaginal dilators). She explained that this was exacerbated by her *partner's physical attributes*. She said “it’s complicated, incredibly, by the fact, that, he is blessed with being overly endowed...So, what used to be ‘Halleluia!’ is now, ‘Oh, my goodness!’” While Maggie expressed that she and her partner could talk about their sexual problems, it seemed as if she might have had *difficulty talking to her partner about exploring alternate ways of being sexually intimate together outside of sexual intercourse*. This was revealed in the following transaction:

I also find that he’s very, *genitally driven*, rather than in the moment, concentrating on other parts of my body, which is covered in, I can’t remember which module... you can start with knees, can start with feet, can start with whatever.

When asked if she and her partner had ever attempted the partner-sensate focuses exercises, she admitted that they had not even tried. She reflected on this and commented that this was likely because, “I think we just want to go for the Preakness...the horse race. Get to the finish line. Just because we can. And then maybe back up and think, ‘Oh yeah, we can do other stuff that’s nice too.’” When asked what she thought it would mean for her if sex was not so intercourse driven, she responded: “Oh, it would be great! Yeah, and we could talk about that! I wish you could talk to him about that.” Later on in our interview, she confirmed that for her it was sometimes *hard to*

talk about sexual matters.

Considering all the struggles she was having in her life, concerning both her sexual difficulties and other life events, it was not surprising that there were long delays in Maggie's progress through the OPES program, "sometimes I felt it to be, and this is just me, it wasn't the program, *I felt too overwhelmed by it.*" Maggie explained how hard it was at times to face working through the OPES program: "I had to leave it. I had to set it aside. It was too close to what I was going through. For one thing, it's based on sexual difficulties, and so – none of that [sex] was happening... some days I just couldn't look at it." With its focus on sexual difficulties, the program seemed to have added to Maggie's distress. She felt there were times when she "wasn't making the honour roll" because she *could not "live up to" the program's expectations* of her progressing through the program modules on a weekly basis. She added, "And I don't think sometimes, or a lot of the times, I don't think that had Jon been able to participate, it would have worked anyway, because my brain was off somewhere else."

Specific to the OPES program, it seemed as if Maggie perceived the formatting of some of the *module questions as lacking sensitivity towards participants' lived experiences*. For example, multiple times throughout her narration, Maggie kept returning to the series of questions that were presented in Module 2 (The Four P's of Sexual Difficulties: Predisposing, Precipitating, Perpetuating & Protective Factors). These questions were intended to encourage participant self-reflection on the broad scope of areas in their lives and development that may have shaped the way they experience their sexuality. These questions brought up significant and sometimes quite troubling memories that she confirmed had a powerful negative impact on her sexual self-perceptions. As well as being distressed by some of these questions, Maggie seemed somewhat confused about the intent behind these questions – thinking perhaps that participants

were expected to respond to them as part of the study. Maggie recalled being very *frustrated with the closed-ended formatting of many of these questions*. She said, “they were YES/ NO questions and at first, they pissed me off because I could answer them with a yes or a no, [but] I thought, yes or no, it’s not...it’s not black and white.” Although she said she understood that the program did not want to dissuade participants from responding, she thought that asking for a simple yes/ no, or quantitative response (i.e., on a scale from 1 to 10) to many questions was “too restrictive” and came across as “cutting off” participant responses. The other problem that she had with these questions was that there was *no forum provided in which she could respond to or elucidate on her responses* to these questions. Reading from the program materials, she recalled her reactions to the questions presented under “Predisposing Factors”:

‘What did your family teach you about sexuality and relationships?’ Well, there’s no opportunity to fill that in, right? I could write a paragraph about that! ‘What did your family teach you about cancer?’ ... ‘What were your early experiences and beliefs about sexuality?’ ‘Was it discussed, or openly condemned in your family?’ UhHuh!!! ‘Was there a forum for asking questions and receiving answers?’ That could be a module unto its own. So yeah, it could become a monster! I understand why it has to be more succinct, but still there was *plenty* to think about...what I would have written as an essay, or a paragraph response, I thought about it in my head.

Motivations: What kept her going through the OPES program? Maggie recalled that it was her *intense curiosity* about what the OPES program had to offer that initially motivated her to participate. On the other hand, during our interview it seemed that Maggie really had to work at recalling what motivated her to finish the OPES program. After some reflection, she revealed her *sense of commitment to the program* and *not wanting to be a quitter*, her reawakened *desire*

to reclaim her sexuality as being a vital part of her womanhood, as well as hope – her enduring hope that her sex life would improve were strong motivating factors.

Maggie commented that her exposure to information that addressed the impact cancer and its treatment had on her sexuality had been extremely limited. When she reflected back to when she received the invitation to participate in the OPES program, she recalled, “Well, my first reaction to the whole program was *intense curiosity*.” She said she wanted to know, “What’s this all about?” and wondered how this program could help her, “not feel like her body and brain were two different entities.”

When asked what kept her going to finish the program, Maggie responded, “That’s a good question...I need to think about it.” After some reflection, she explained,

I don’t like giving up. I don’t want to give up. And I didn’t want to let you down in your study. Because you did hang in there with me, when I’m sure there were, I know there were times, that I didn’t answer your emails, I didn’t get back to you quickly, and you must have thought, “For God’s sake! This is my life’s work!”

This degree of commitment did not appear to be an unusual aspect of Maggie’s character as she also mentioned being very involved with an organization that advocates for improving patient-centered health care even though it sometimes felt like it was not worth her time or effort. Maggie also shared that she volunteered with a cancer peer-support organization. She said her ongoing involvement in helping other cancer patients has helped a lot in her own emotional healing after cancer and having the ileostomy.

Despite her challenges with some of the modules and questions, Maggie clarified that the OPES program wasn’t always an overwhelming task for her. There were times when she felt the program helped her *realize what she wanted with regards to her sexual wellbeing*, and gave her

plenty to think about. It also seemed as if she perceived the program as permitting her in a way to seek other's help in not only solving her sexual problems, but also addressing her distress that her lack of sexual desire, interest, or receptivity meant she was somehow less of a woman. This appeared to have inspired her at moments to continue working through the program:

There were some parts I was able to read and think, 'Yes! This is what I want to happen!'

An overall feeling that I don't have to be in charge! Can I just let this go and let somebody else help me with this? Can I let my partner take over this part? The anxiety of not being a woman anymore. I wasn't willing to let that go.

For Maggie, it seemed as if she associated wanting to *reclaim her sexuality and regain a sexually satisfying life* like she had pre-cancer, as *being vital in her recuperation of her sense of herself as a woman*. In her words: "I still wanted to be a vibrant sexual woman even though I didn't feel it in either brain nor body. But some part of me still wanted that and still does."

Another theme that arose several times throughout her narrative was *hope*. Maggie imagined that participants in the OPES program, including herself, carried through until the end of program due to *the hope they had that their sexual lives would improve*. In her words: "Hope! Hope, I think, the human factor within us that just wants to make it better." Even though she felt she had been negligent throughout her participation in the program, Maggie said she would "definitely do it again." Importantly, she qualified this with the following, "I'm at a different place in my life. I still have medical factors, but I'm not sick anymore." She added her mood has also greatly improved compared to how it was when she participated in the OPES program.

Benefits experienced from participating in the OPES program. Maggie found the most beneficial aspects of the OPES program included the *module format and information* that helped her *focus on her sexual difficulties and think about her sexual problems from another*

perspective. The material covered in the program seemed to have *helped her feel less guilty about the lack of sexual activity* in her relationship. She also thought the program material would serve as *a useful resource* going forward.

Reflecting back on her experiences with the OPES program, the first thing Maggie recounted as being the most important aspect of the program for her was the *“module setup.”* She found the consistency of starting with one topic “which lead to another, and then another, and so on” was helpful for her. Maggie felt that the *structure of the program*, and the questions that were proposed in the modules, were necessary to help her begin to address her sexual difficulties. In her words, “I think you need that structure in order to get people talking about it, or writing about it, thinking about it for sure, and then responding to it.”

Maggie recounted how participating in the program *provided her with a lot of things to think about* with regards to her sexual wellbeing. Although Maggie had been frustrated with certain questions, she also said, “I found them really helpful... I think they’re really good, if nothing else, a really good starting point and beyond... *plenty for me to think about.*” She added that the OPES program got her thinking “outside the bubble wrap,” and helped her *focus on issues outside of cancer that were also likely impacting her sexual wellbeing*, such as her anxiety as well as formative events in her past. The information presented through the modules appeared to have helped Maggie begin to see her sexual difficulties from another perspective, thereby *helping to lessen the culpability she recalled feeling about her lack of receptivity to sexual activity*:

I think what the program did for me, right from the get go, was to bring attention for myself to all the modules, to what was happening with my body. I don’t know where I ever would have found that without this program. As far as I know there’s nothing else

out there.

Participating in the OPES program also reminded Maggie that *sexual intercourse was not the only aspect of sexual wellbeing*, or at least, it lead her to question the common perception that intercourse is the most important aspect of sexuality. She recalled that the program helped her pay attention to what was important in her relationship aside from sexual activity, such as how much she valued their shared “humour.” As she reflected on this Maggie said, “That’s why this module that talks about just canoodling, for want of a better [word]...is so important because – don’t you think we’re so intercourse oriented? And society tells us that it’s *the guys* who want to do it. And women want more canoodling.”

Despite not really feeling like she was in the right head space to concentrate and apply herself as fully to the OPES program as she would have liked to at the time, Maggie did reflect on the program as *being a useful resource* that she could continue to use moving forward especially relative to her relationship with her partner. She commented that in reviewing the OPES material prior to our interview, she thought, “I can see where that is going to be important for my partner and me.” The physical exercises and the section on relationship enhancement were two areas of the program she felt were especially deserving of her attention, “Reading through that, last week, especially when he was here, was really a tune up for me.” In reflecting on times when she unable to complete certain partner-involved parts of the program Maggie recalled:

...at least I was able to consider it, to reflect on our past experiences with it. And, hopefully make plans to use that module in the future. I think this program probably helps...you can revisit it over and over again. This is what we could be doing. This is what we did before. We haven’t done this before, let’s try this now.

She acknowledged that having a willing partner was also an important part in continuing to use the OPES program. In her words: “I’m lucky to have a partner who is open to that...I can think of lots of partners in my past who’d say, “You kidding?!?”

Maggie also discussed that she did not know where else she, or other cancer patients, could possibly find the sort of information that was provided in the OPES program. She explained that the organization she volunteered with “is always looking for this kind of thing to help people who are in total distress and have nowhere to go, nobody to talk to.” This was important for Maggie because she recalled, “when I had cancer, there was nobody for me.” It was not until she “accidentally” found an online peer support group, a psychotherapist, and later the OPES program, that she said she had access to this sort of information or support. In summarizing her perception of the OPES program, she said: “I think it’s a good start. Part of me felt like it was, the technical part of *it was great...in being informative.*”

Where she is now after participating in OPES. Maggie was initially concerned about what she was able to offer by participating in this interview and warned me that *sex, “just isn’t happening yet.”* Her sexual difficulties were ongoing and many of the troubles that hampered her progress through the OPES program, continued to impact her ability to recapture a pleasurable sexual life. These included her IBS, vaginal atrophy, inability to tolerate penetration, low libido, and difficulties with body image and low self-esteem. In addition, her partner also struggled with depression, IBS, low self-esteem and sense of inadequacy, erectile dysfunction, and some recent troubling health problems (i.e., a colon cancer scare). Maggie shared how they tended to *blame themselves for the difficulties in their sexual relationship:*

Now he says things like, “No, it’s my fault. I have ED.” And I’ll say, “No, it’s my fault. I have stenosis, and my body has atrophied.” And we’ve talked about this, using those

medical terms, and that honesty has been really important. At first, I felt guilty about it.

About *my* lack of ability to perform...bad word...my ability to enjoy our relationship.

Maggie also discussed how her *anti-depressant medication* has “*shot my libido right to the bottom of the pond*” and that “as much as my body is willing, my mind has not.” She explained how her medications sabotaged her attempts at finding any pleasure in sexual activity. In her words: “we can have lots of foreplay, and that’s not always comfortable for me either because the antidepressants are in control... they sabotage my efforts at helping myself.”

Maggie recollected a couple of occasions after the OPES program, when she and her partner had made a concerted effort to reignite the sexual flame by attempting to have sexual intercourse:

Straight to the Preakness, finish line. And for me, I didn’t mind that. It was like that was my goal too. Let’s just get this done because I’d like to see this done. It would be great for this to be done...Just to go! Let’s give’r! And, it didn’t happen.

Even though she said they were both “okay with this” at the time, she admitted, “I can’t say I wasn’t disappointed. But I always feel, damn it! Things are just so shut down, down there.” She also shared how just the week before our interview, her partner “had made it a quest for us to at least do something about it, and get intimate, and be where we were a long time ago.” Armed and successful with his Cialis, and Maggie prepared after using her estradiol cream, she exclaimed, “Oh my God! I saw stars! It was so painful!” Although Maggie said she was “frustrated as hell,” she said she recognized this was the first attempt they had made in a long time and said they both had agreed that they would just need more practice. Despite her disappointment, she believed *improvements had been made*, such as *talking more* about what happened and what they could try differently next time. Maggie also shared that another positive

change in their relationship was that they had *cuddled in bed, falling asleep spooning, for the first time since she had her ileostomy*. While Maggie continues to maintain hope she also confessed, “I vacillate between being very hopeful, and thinking, “Ahhhh, it’s never going to be the same.”

Advice on how the OPES program might have better met her needs. Although Maggie appeared to struggle with imparting any advice or feedback about the OPES program, after some reflection she discussed her perception that *the first module was a weak introduction* to starting a program geared towards helping participants with sexual difficulties following cancer treatment. She referred back to the very first question that was intended to help participants get a sense of how important sexuality was for them by rating various aspects of life on a scale from 1 (not important at all) to 10 (extremely important). While she exclaimed, “a loving relationship – Well, I think we all want to have that, so that’s a 10! A rewarding sex life, I continue to hope,” she did not understand how asking participants to rate the importance of having such things as a successful professional life, or a rich cultural or spiritual life, were related to sexuality. She commented, somewhat hesitatingly, “This was kinda, I don’t know – And this was module 1! This is what got us started on this whole journey. I kinda didn’t get it.” Maggie also wondered if the OPES program may have been “gender specific,” in being more appealing to women’s perceptions of sexuality than men’s. She also commented that the program did not address sexual orientation, and that it did not touch on the sometimes devastating effect of hot flashes post-cancer treatment.

Maggie also reiterated her frustration with various *OPES program questions that did not provide an opportunity for her to include a personal response*. She also shared her thoughts on certain OPES quantitative measures: “Some of it is too finite to be human, cause we’re not finite,

we're all over the map.” As she reflected on tweaking this aspect of the program, Maggie expressed her *lack of understanding on what happens to the data* she and other participants provided in their online responses. “Where do these numbers go? Do we ever find out if there’s a majority that feel if [a rewarding sex life] is ‘Not at All Important,’ or ‘Extremely Important,’ or a somewhere in between?”

Although Maggie did not explicitly suggest that the OPES program needed to increase its therapeutic or peer support, she did discuss how valuable the affirmation, support, and information she received from personal psychotherapy and an online peer support group were in her recovery after cancer. She felt her personal psychotherapy, which coincided with her participation in the OPES program, was “absolutely helpful.” She added, “My psychotherapist had uterine cancer. And her husband had a colostomy bag. So, she had a whole lot of information before I even saw her.” Maggie also discussed the positive outcomes of having participated in an online support group prior to participating in the OPES program:

...they helped so much! I laughed my way through like 3 months of feeling like shit! Because I felt like crap, and looked like crap, and to me, there was no hope...And so they talked about vaginal dryness, and all the things that I was going through...feeling like shit around your partner...It was all there.

The recognition of common struggles and ensuing laughter shared among fellow female cancer survivors provided Maggie with great relief suggesting the need for including more psychosocial support during the OPES program.

Common Themes and Subthemes

The following table represents my interpretation of the common themes and subthemes drawn from the women's experiences of working through and completing the OPES program, as well as their personal feedback on how the program could have better meet their needs.

Aspects of OPES	Common Themes
Participation	<ul style="list-style-type: none"> • Subthemes
Motivations to Complete Program	Supportive Partners and Relationships <ul style="list-style-type: none"> • Pre-existing level of comfort and openness in long-term relationships • General relationship satisfaction • Partners' support of and interest in the OPES program
	Responsibility <ul style="list-style-type: none"> • Sense of commitment to the program • Accountable to following through on commitments
	Desire to Help Others <ul style="list-style-type: none"> • Desire to contribute to cancer research • Helping cancer patients/survivors as meaningful experience
	Desire to Improve Sexual Wellbeing and/or Marital Relationship <ul style="list-style-type: none"> • Satisfying sexuality pre-cancer • Intimacy an important aspect of relationship (not necessarily sexual) • Sex perceived as an important aspect of intimate relationship and a healthy or full life • Aspect of fear of losing partner or intimate connection
	Willingness To Go Beyond Comfort Zone <ul style="list-style-type: none"> • Open-mindedness • Courage to try new things
Challenges Faced	Time Commitment <ul style="list-style-type: none"> • Significant time spent completing homework exercises • Requiring more than one week to complete each module • Frustration with program time constraints
	Openly Discussing Sexuality or Sexual Relationship <ul style="list-style-type: none"> • Difficulty in discussing own sexual needs and/or fears, especially with partner • Ambivalence/disinterest towards using the discussion board

Aspects of OPES	Common Themes
Participation	<ul style="list-style-type: none"> • Subthemes
Challenges Faced	<p>Addressing Sexual Problems after Prolonged Period of Avoidance</p> <ul style="list-style-type: none"> • Struggle bringing attention back to sex • Arising distress when beginning to address sexual changes post-cancer treatment • Reintegrating sexual activity into relationship after long period of abstinence • Struggle reconnecting with partner physically (sexually or non-sexually)
	<p>Ambivalence Towards Various Aspects of Program Content</p> <ul style="list-style-type: none"> • Uncertainty, dissatisfaction, and/or discomfort around using certain erotic aids • Frustration with quantitative or closed-ended questions that did not provide options to expand on responses • Confusion on interpretations of and purpose of quantitative questions
Perceived Benefits	<p>Bringing Attention [Back] to the Importance of Sexuality in One's Life and Relationship</p> <ul style="list-style-type: none"> • Provided opportunities for self-reflection and thinking about sexuality and sexual relationship
	<p>Providing Information Perceived as Not Otherwise Accessible (indirectly within each story or validation interviews)</p> <ul style="list-style-type: none"> • OPES information and material was enlightening • Learning about sexuality and sexual problems after cancer • New ways of understanding sex and sexual response
	<p>Increased Intimacy, Openness, and/or Closeness in Relationship (sexual and/or nonsexual)</p> <ul style="list-style-type: none"> • Opening or increasing dialogue with partners about sex • Increased comfort in discussing sex
	<p>Program Format and Structure</p> <ul style="list-style-type: none"> • Ease of accessing program online • Focus on one topic at a time • Self-directed pace • Ability to revisit module as many times as needed
	<p>Useful Resource and Guide</p> <ul style="list-style-type: none"> • Providing concrete things to think about or try (i.e. activities) • Opening a door, providing a pathway, concrete steps to take • A useful resource to refer back to

Aspects of OPES	Common Themes
Participation	<ul style="list-style-type: none"> • Subthemes
Current Sexual Wellbeing (Post-OPES Program)	Cancer-Treatment Related Difficulties Impacting Sexual Activity <ul style="list-style-type: none"> • Vaginal atrophy & painful intercourse • Gastrointestinal distress (among women who had radiation treatment)
	Lack of Improvements in Sexual Desire, Interest, and/or Frequency <ul style="list-style-type: none"> • Expressed lack of sexual activity
	Ongoing Successes in Maintaining and/or Improving Relationship Intimacy (sexual and/or nonsexual) <ul style="list-style-type: none"> • Enduring hope that sexual wellbeing will continue to improve with time, effort, and attention • Making future plans for increasing sexual intimacy
OPES Program Feedback – How OPES Could Better Meet Needs	Increase Interpersonal Contact and/or Support <ul style="list-style-type: none"> • Increasing access to peer and/or therapeutic supports • Providing feedback and/or responses to participants' questionnaire responses or homework entries • Discussion board largely unsuccessful in offering peer support • Opportunities presented to trouble-shoot difficulties faced in program with program facilitator
	Assessing Individual Needs <ul style="list-style-type: none"> • Is timing of participation in program appropriate for each participant? • Appropriate referrals/ suggestions re: further health care professionals for non-psychologically oriented needs in addition to program (i.e., gynaecologists, ostomy-care services, pelvic floor physiotherapists)
	Tailoring Program to Meet Individualized Needs <ul style="list-style-type: none"> • Allowing more time to complete modules • Flexibility in order of modules • Option of skipping certain modules • Option of partner inclusion/ participation • Providing relevant information on sexual pain • Providing relevant information on sexuality and ostomies
	Providing Information on Anticipating Difficulties with Participation (i.e., Module 12) at Onset <ul style="list-style-type: none"> • Normalizing program difficulty • Validating difficulty inherent in addressing sexual difficulties

Distinctive Themes Among Narratives

It is pertinent to address the following three important differences between the six women's narratives: the degree of psychological distress experienced among these women when working through the OPES program; the participants' reactions to erotic aids and the sensate-focus exercises; and what aspects of the program each of the women found most helpful. Three of the six women (Terry, Lisa, Maggie) expressed having experienced a great deal of psychological distress during their participation in the OPES program that not only negatively impacted their experiences and success with the program, but also exacerbated their distress at times. A significant contributor to the distress these women experienced was related to the profound impact cancer and its treatment had on their physical integrity and ability to experience sexual pleasure or joy. According to Terry and Maggie, their sexuality prior to cancer was a highly valued and satisfying aspect of their self-perceptions and relationships, and it appeared as if they continued to struggle with this loss during their participation in the program.

It was also evident that for some of these women, some OPES modules or exercises that had them focus on their current sexual difficulties (e.g., reflecting on predisposing factors aside from cancer that could be contributing to their sexual problems; genital exploration exercises) triggered difficult thoughts, emotions, and memories. For example, Natasha and Maggie commented on how amazed they were to realize that childhood events could still be impacting their sexual self-perceptions and wellbeing in late adulthood. Not all women faced these difficulties to such a great degree during their participation. In fact, Pam and Paula acknowledged that their lack of psychological distress likely facilitated their continued participation in the program. For those women who really struggled through the program (Terry, Lisa, Maggie), it was not surprising that they revealed it was challenging to remain motivated to

complete the program, that there were sometimes long delays in their progress, that the program often “felt like work” or was “overwhelming” at times, and that there were moments when they felt like dropping out. What is also important to note is that these women revealed some concern over not being “good participants” or “not meeting the study’s expectations.”

It was also interesting to note the participant’s varied reactions to the modules on erotic aids and the sensate-focus exercises. These aspects of the OPES program were raised spontaneously in each woman’s narrative. Some women (Lisa, Terry) were not able or willing to complete the sensate-focus exercises, especially with their partners, because of the degree of anxiety or distress these exercises triggered, and/or the fear they would lead to sexual activity. The partnered sensate-exercises also required a willing and available partner, which was not the case for every woman (Maggie, Paula). On the other hand, other women (Pam, Natasha) found these exercises to be quite enjoyable and reported that they were the most helpful aspects of the program. The participants’ reactions to the module on erotic aids were also quite varied, especially their response to the suggestion of incorporating the use of a vibrator to increase their sexual arousal and pleasure. Pam, Paula, and Natasha discussed how they found incorporating vibrators into their sexual activity to be quite helpful in increasing their sense of sexual pleasure, and that to their surprise, their husbands were not perturbed by this addition to their sexual repertoire. According to Natasha’s story, it seemed as though she and her husband experimented with sexual toys in the early years of their relationship which may have made this exercise easier for them compared to the couples who had not previously incorporated erotic aids into their love-making. For Terry, living in a small city without access to appealing places to purchase erotica was a significant barrier to completing this exercise, and Lisa did not achieve any pleasure from attempting to use a vibrator – in fact she found it “annoying.”

These various reactions to the modules on erotic aids and sensate-focus exercises overlap with the third important difference that was revealed between these narratives –that women found very different aspects of the OPES program helpful in addressing their sexual difficulties at the time of their participation. It is possible that this coincided with where each woman was in her own post-cancer treatment sexual recovery. For instance, Terry found the modules on relaxation and mindfulness, as well as relationship communication, were the most helpful areas that she felt she needed to concentrate on throughout her participation in the program. She revealed she had not been ready when completing the program to tackle the more physically- or sexually-oriented activities in the program. Lisa also found the more genitally- or physically-oriented activities too challenging and distressing for her to address, but that starting to communicate her feelings and experiences to her husband was crucial in improving her sexual wellbeing. On the other hand, Pam and Natasha found that the partnered activities and practical components of the program successfully addressed what they needed in improving their sexual wellbeing and relationships. It appeared that Maggie was at a place during her participation where acquiring information was the most helpful aspect of the program. This also seemed to be a very important aspect of the program for Paula.

Chapter 5: Discussion

The research question posed in this narrative study was: *How did women experience the OPES online psychoeducational program for sexual difficulties after cancer treatment, and what changes did they experience in terms of their sexual lives and relationships, during and following completion of the program?* The purpose of this chapter is to discuss the implications of the findings from this exploratory investigation in light of the limitations of this research. In addition, these findings provide formative feedback for the future development of the OPES program, or similar online interventions. Suggestions for future research in the area of psychoeducational or similar psychologically-oriented treatments for sexual difficulties following cancer treatment will also be discussed.

Putting the Research Findings in Context

In discussing the implications of these findings it is first important to put the study and sample into context. The current research shares the same limitations common to narrative inquiry (Riessman, 1993). The sample size was small and included only six of the 36 women who completed the OPES program. In addition, these women were all in heterosexual, long-term committed and highly satisfying relationships and so are not representative of women who were in casual or newer relationships, or in strained/ poorly functioning relationships during their participation in the program. We do not know the extent to which the findings reflect the experiences of the women who dropped out of the OPES program, or those who completed the program but did not participate in this study. Also, these women's experiences are not likely to be representative of those experienced by male survivors of colorectal cancer who either withdrew from, or completed the OPES program.

In this study, during in-depth interviews, the women shared their experiences of participating in the OPES program. As the researcher, I then identified the common themes I interpreted as salient in these women's stories. This does not infer these themes are common for all women and men who participated and completed the OPES program, and especially for those who did not complete this program. This also does not assume that another researcher would analyse these transcripts and come to the same conclusions I have. It is difficult as well as inappropriate to make generalizations from analyzing this series of personal narratives across all cases of people who participate in psychologically-oriented sexual rehabilitation interventions after reproductive or colorectal cancer and its treatment. It is also important to note that anywhere between 13 months and three years had passed since these women completed the 12-modules of the OPES program. The wide variance in time since program completion may well have had an impact on their ability to recollect more nuanced aspects of their experiences with the OPES program.

Implications of Research Findings

The following discussion will focus on how the common themes and subthemes found in this research inform program developers, researchers, and/ or clinicians on the needs and motivations, successes, and challenges experienced by participants who completed the OPES program, as well as the motivating factors that assisted them in completing this intervention. How these findings compare to the literature on other psychoeducational interventions covered in Chapter Two will be addressed. Results from this study will also be compared to qualitative findings from semi-structured interviews with 19 participants who completed the 4 in-person sessions of the original psychoeducation intervention (PED) from which the OPES online

program was modified and developed (Brotto et al., 2008). The implications these findings have for the future development of the OPES program and similar interventions will also be discussed.

Women's sexual health care needs and motivations for engaging in the OPES program. The results from this study confirm there is a high need for psychologically-oriented programs that attend to the sexual health and intimacy concerns for women in the aftermath of cancer irrespective of whether cancer is treated with hormone therapy, surgery, radiation, chemotherapy, or temporary ileostomies (Bober & Varela, 2012; Tierney, 2008; Sadovsky et al., 2010). The women in this study elected to participate in the OPES program because they felt they needed help reconnecting with and enjoying their bodies, regaining interest in sexual activity, experiencing sexual pleasure again, and recovering the shared physical and sexual intimacy they had previously enjoyed and valued with their partners prior to cancer. Also, consistent with the research indicating a lack of cancer patient access to sexual health information (Bober & Varela; Hordern, 2008; Hordern & Street, 2007; Stead, Brown, Fallowfield, & Selby, 2003), these women were in need of acquiring pertinent information that could address their sexual concerns after receiving these “life-saving” treatments. Some recalled that the invitation to the OPES program was the first time they received information about, or an offer to help them deal with their sexual problems following cancer. This finding reflects similar participant feedback provided on the original PED (Brotto et al., 2008) from which the OPES program was modified – sexuality is important for women after cancer and they would have welcomed this information earlier in their cancer treatment. Despite low recruitment rates found in the OPES program and other researched interventions (e.g., Brotto et al., 2008; Rowland et al., 2009), the results of this study confirm there is an ongoing need among cancer survivors of

various ages to have access to information and professional help with their sexual and intimacy concerns at various stages in their recovery, even years after having completed treatment.

Successes with the OPES program. Overall, the results from this study indicate the OPES program was perceived as a worthwhile experience, although not always an “enjoyable” one. The women interviewed explained that the OPES program was a “good start” in its intentions of helping cancer survivors with their sexual difficulties post-cancer treatment. These women, like those who participated in the face-to-face PED (Brotto et al., 2008), were all pleased to have participated in the program and study. These findings are also consistent with feedback provided by participants on other similar psychoeducational interventions addressing quality-of-life issues and sexual concerns after cancer (i.e., Rowland et al. 2009; Wiljer et al., 2011). Taken together, these types of programs are meeting a need among cancer survivors and are generally well received, deemed to be worthwhile, and to some degree are helping women address their sexual difficulties post cancer treatment.

The OPES program appeared to be successful in providing these women with relevant information on sexuality and cancer that they did not recall receiving much of, if any, during or following their cancer treatment. The women in this study felt the modules gave them new things to think about and offered them new ways of understanding their sexual response after cancer treatment. This information apparently lessened some of the distress or guilt these women felt about their lack of sexual interest and inability or unwillingness to be sexually active. This coincides with other research that has found providing relevant sexual health information increased women’s knowledge and was beneficial in enhancing women’s emotional wellbeing and quality of life (Schover et al., 2011, 2013; Wiljer et al., 2011). The importance of providing pertinent sexual health information in helping women with their sexual concerns is a consistent

finding among research on the effectiveness of psychoeducational interventions for women who have had reproductive cancer (i.e., Schover et al., 2006, 2011). Considering many patients are not receiving adequate information on sexual health in the aftermath of cancer, programs such as OPES may be the only means by which participants are accessing education and support in addressing their sexual quality of life concerns.

This is an area the OPES program could be even further developed. For example, missing from the program was relevant information covering sexual pain – a commonly experienced barrier that prevented some of these women from enjoying sexual intimacy and having sexual intercourse. If women are unable to have sexual intercourse without pain, suggestions could be provided on helping women and their partners expand their sexual repertoires to include less painful and more satisfying sexual activities for example (Ussher, Perz, & Gilbert, 2014). Also missing from the OPES program was specific sexual health information pertaining to living with an ileostomy or colostomy. Considering half of the women in this study reported a complete cessation of sexual activity during the period they had a temporary ileostomy, the reality of living with a stoma and ostomy bag may be a tremendously difficult barrier to overcome in recovering sexual intimacy. The OPES program would be greatly improved by including material and suggestions for participants who struggle with the physical realities of an ostomy.

The women in this study felt their participation in the OPES program was successful in bringing their attention to the importance sexuality had in their lives and relationships, after a long period of avoidance. This appears to be a common and highly valued benefit that women who participated and completed either the online OPES or the face-to-face PED derived from completing these programs – both programs helped women recognize that their sexual wellbeing indeed continued to be a very important part of their lives despite their difficulties after cancer

(also see Brotto et al., 2008). Apparently, participating in either program also improved women's *hope* that their sexual wellbeing would improve with time and effort (Brotto et al.). Therefore, instilling hope appears to be an important benefit these programs can provide that help keep women motivated to pursue their goals of sexual wellness. Even if the OPES program did not result in any behavioural changes or physical improvements for some participants, it provided women with opportunities to think more deeply about their sexual wellbeing, and encouraged self-reflection including on what they wanted. Helping women determine what they want in terms of their own sexual needs and desires would be a very empowering aspect upon which these types of programs should be built and broadened on in the future.

The participants particularly valued the way in which their participation in the OPES program helped them improve the level of intimacy they shared with their partners. Several of the participants reported how participating in the exercises helped them achieve a new level of openness, understanding, and closeness between themselves and their partners, even if there was not necessarily an improvement in “sexual activity” per se. This is interesting considering quantitative results of the OPES program indicated no relationship improvements from pre- to post-intervention. This has a couple of important implications. First, researchers' and participants' perspectives on program goals may be quite different. Researchers' goals are focused on participant improvement in specific end measures such as sexual functioning or dyadic adjustment while participants' goals vary, are multidimensional in nature, and not easily measured. Program developers and researchers of psychologically-oriented sexual rehabilitation programs may need to rethink their goals (i.e., improving “sexual functioning”) and measure “success” in a way that is more inline with participants' needs and goals. Secondly, as discussed

in Chapter 2, quantitative measures of “sexual functioning” may be missing the mark in terms of the value of these programs from participants’ perspectives (e.g., Maughan & Clark, 2001).

The results of this study suggest that the breadth of topics covered in the OPES program were successful in offering something of value to each woman, whether it was relaxation and mindfulness training, recommendations on where to buy erotic toys, or encouragement to open up and discuss her sexual fears with her partner. If participants found they were not ready or willing to complete an exercise, they explained that the program materials were still helpful as a future resource or guide that they could revisit if and when they were ready. This speaks to the individual needs and differences among women participating in interventions such as the OPES program (Cleary & Hegarty, 2011; Gilbert, Ussher, & Perz, 2010, 2011). For example, the genitally- and sexually-oriented exploration exercises may have been more acceptable to participants who were psychologically and/or physically recovered from their cancer treatments as was also discussed by Brotto and colleagues (2008) with regards to the in-person PED. Consequently, program benefits need to be understood in the context of where each woman was in her process of emotional and physical healing, needs and expectations. As a result, the value that participants receive from such interventions as the OPES program cannot always be easily measured.

Challenges with the OPES program. Many women found the time commitment involved in completing the program to be overly demanding. Among the few studies that have captured this information, the significant time commitment involved in these types of programs (both in-person and online) appears to be a common barrier for participant recruitment and retention among women who have had cancer as well as those who have not (i.e., McCabe & Jones, 2013; Rowland et al. 2009). Indeed, despite all but one participant being retired at the

time, none of the women in this study were successful in completing all the modules on a weekly basis or the full program in the proposed 12-weeks. In its current form, completing each OPES module on a weekly basis was not a realistic expectation for the vast majority of participants. This may help account for the high degree of attrition observed in the OPES study. Interestingly, while recruitment rates were also low for the face-to-face PED, higher participant retention (19 out of 22) and rates of homework compliance were reported in the PED (Brotto et al., 2008). This difference between the online OPES and face-to-face PED could be related to the longer length of time between sessions in the PED (4 weeks) allowing participants more time to work on completing the homework exercises. Future programs could consider providing modules on a bi-weekly basis. It would be useful to explore whether the degree of content or the extent of proposed homework in various modules could be condensed in future editions of the OPES programs. Alternatively, participants could be provided with a summary of each module and the rationale behind proposed exercises, and permitted to complete those modules that are most pertinent to their needs and interests.

While 12-weeks is a long commitment to ask of participants, this seems to be the norm among similar online interventions (Classen et al., 2013; Schover et al., 2013), although these programs also suffer from high attrition. Participants who completed the 12-week online GyneGals program found this amount of time was appropriate for this type of intervention (Wiljer et al., 2011). This echoes comments made by some women in this study that it would be difficult to cover all the necessary and multifaceted aspects of women's sexual wellbeing after cancer in any less time. In addition, one yearlong 16-session individualized counselling intervention achieved a 75% completion rate (Marcus et al., 2010) suggesting the need for long-term support. Providing more individualized support and flexibility in module expectations, as

well as allowing participants to have more control of the timelines may help to engage participants in working through lengthy interventions (see Donkin & Glozier, 2012). On the other hand, the individualized support that is inherent in face-to-face interventions, such as the in-person PED (Brotto et al., 2008), could also account for the higher program adherence and homework compliance observed in these programs compared to online interventions.

Results from this study indicate that when various technical difficulties in the program arose, this caused a great deal of frustration for the program participants, so much so that one woman admitted she contemplated dropping out of the program at these times. Interestingly, quantitative results of the OPES study indicated a mean rating for experiencing technical difficulties with modules that corresponded to halfway between “not at all” and “a little.” This was contrary to this study’s results, as well as my own experiences as a research assistant – I read several discussion board posts and received many emails and telephone calls from participants about various technical difficulties. Unfortunately, it is unknown to what extent technical problems negatively impacted participants’ experiences of and motivation to complete the OPES program. Furthermore, considering participants likely varied in their level of experience and comfort with using computers and accessing information online, the OPES online format may have been easier and more helpful for some participants to use than others. In future screening interviews, assessing participants’ level of experience with using computers can indicate which participants may require more technical support throughout their participation in such online programs. Paper copies of program materials and compact discs of audio-recordings could be made available for individuals more comfortable using those mediums.

The women in this study also struggled with a certain degree of ambivalence towards certain aspects of the OPES program. Certain modules or suggested activities did not seem

relevant to some women or their problems, and some may not have been realistic given where a woman was in terms of her readiness or the physical realities she was contending with. For example, many of these women faced incredible challenges in surpassing social (and perhaps generational) conventions to explore their sexuality, discuss their sexual needs and fears with their partner, and defy the negative messages they had learned about masturbation in order to purchase erotica, let alone use erotic aids. Furthermore, such physically intimate exercises as genital exploration and partner-involved sensate focus exercises seemed perhaps premature for women who were having difficulties with anxiety and relaxation, communicating their needs to their partner, or fear of physical intimacy leading to intercourse. However, this was not the case for other women both here and in the PED (Brotto et al., 2008) who reported that arousal-enhancing exercises (i.e., sensate-focus) and sexual aids (i.e., using a vibrator) were quite helpful in increasing their sense of genital pleasure. The results in the present study reveal the various ways in which the bio-psycho-social (as well as environment and historical) dimensions of these women's lives are interrelated and influenced how they experienced the OPES program. Therefore, these findings highlight the importance of assessing and tailoring such psychosexual interventions as the OPES program to the unique needs of each individual participants as has been suggested by others in the cancer and sexuality literature (e.g., Bober & Varela, 2012; Cleary & Hegarty, 2011; Taylor, Harley, Ziegler, Brown & Velikova, 2011).

Those psychologically-oriented interventions that approach sexuality from a multidimensional perspective and were individualized to participants' specific needs (i.e., Ayaz & Kubilay, 2009; Ganz et al., 2000; Jeffries et al., 2006; Marcus et al., 2010; Maughan & Clark, 2001; Reese et al., 2012, 2014) seemed to have been most successful in retaining participants as well as being helpful in improving participants sexual wellbeing (Bober & Varela, 2012; Brotto

et al., 2010; Cleary & Hegarty, 2011; Gilbert, Ussher, & Perz, 2010). On the other hand, many of these interventions involved in-person or telephone-based counselling with an experienced health care professional (in sexuality and oncology). Therefore, it is difficult to determine the degree to which the interpersonal contact versus the individualized approach is more or less, or equally, beneficial. Nonetheless, structured psychoeducational interventions addressing cancer survivors' sexual problems, especially those offered online with minimal interpersonal contact, run the risk of presenting a "one size fits all" program that limits the degree to which it can meet participants where they are in terms of their needs and readiness. This may alienate a number of participants enrolled in such programs and could possibly explain the high degree of participant withdrawal (i.e., Donkin & Glozier, 2012; Rowland et al., 2009; Schover et al., 2013).

The frustration with various quantitative or closed-ended questions observed among women in this study may also be related to the lack of personalization in the OPES program. This degree of participant frustration with standardized questions embedded throughout these types of programs has also been found to be a factor impeding participants' motivation for completing structured psychologically-oriented online interventions (Donkin & Glozier, 2012). It has been suggested by participants that including free-text box options with quantitative questions would be beneficial in allowing them to expand on their responses throughout the program. Donkin and Glozier argue that this would increase participant engagement with such online interventions.

Considering the findings here and in the literature, the OPES program would be further strengthened if it was more tailored to meeting participants' individual needs and the physical, psychological and relational circumstances that impact their sexual wellbeing. Therefore, it would be pertinent to have more thorough screening interviews with participants in order to

better understand their physical realities and their most salient sexual health and relationship needs, as well as determining whether the timing of the program is appropriate given where they are in their psychological and physical healing after cancer treatments. Assessing potential barriers prior to participation may also help participants (and program facilitators) anticipate and be better prepared for difficulties that may arise for individual participants in working through such program. For example, it would be helpful to include Module 12 of the OPES program, “Anticipating Difficulties,” earlier in the program rather than later. Another avenue worthy of exploration is reducing program modules to only those modules that are of interest to a participant, with the option of adding modules in a later “intermediate” or “advanced” program. This could also help address the burden of committing to completing a 12-module program where only a portion of the program is relevant for a participant. Furthermore, referring participants to additional health care professionals (e.g., gynaecologists with experience in sexual medicine and cancer; pelvic floor physiotherapists) who could address participants’ physical needs would likely be a welcomed addition. Adjusting structured online programs in such a way to better meet the specific sexual needs among cancer survivors is worthy of attention in future program development and research.

Finally, although it was not referred to as a challenging aspect of the OPES program per se, many of these women struggled with the lack of human contact and feedback in the OPES program. In addition, the discussion board was not found to be helpful. Lack of interpersonal support, interaction, or feedback has also been found to be a common complaint among participants in online psychological interventions, making it difficult for members to engage in these types of programs (Donkin & Glozier, 2012). When examining *quantitative* indicators of program success, the additional benefit of providing supplemental counselling sessions with

psychoeducational interventions (online and non-online) has been equivocal (Schover et al., 2011, 2013). However, participant reports indicate that additional in-person counselling was more helpful in addressing their emotional wellbeing than the online intervention used as “self-help” alone (Schover et al., 2013). In addition, it has been argued that adding interpersonal/human support actually increases effectiveness of and enhances adherence to online psychological interventions, at least in part through supportive social accountability (Mohr, Cuijpers, & Lehman, 2011). The *in-person* support provided in the original PED (Brotto et al., 2008) may therefore account for some of the differences noted between it and the OPES program such as higher program adherence and homework compliance. Therefore, the OPES program would likely be strengthened by increasing the degree of interpersonal contact and therapeutic support available to participants. For example, providing specific feedback to participants’ online responses on homework exercises and commentary would likely increase participant engagement with the program material and rectify misunderstandings, answer specific questions, offer alternative suggestions/ resources, and help participants brainstorm ways to overcome barriers experienced throughout the course of the program. Authors state that it is important online treatment programs not sacrifice “the active ingredients in face-to-face therapy” (Hucker & McCabe, 2014, p. 67). The OPES program could increase its effectiveness by providing additional therapeutic support (with an experienced professional) to those struggling with distressing psychological, physical, or relational realities that are impeding their engagement with the program. In addition, exploring alternative ways of improving engagement in the online discussion board could also be one avenue of increasing interpersonal support in the OPES program. Other online interventions intended to help women with their sexual difficulties have had much more success in facilitating this type of support, such as GyneGals (Classen et al.,

2013) and PersuingPleasure (Hucker & McCabe, 2014). However, these online chat groups were developed with the intention of providing therapeutic “group support” in addition to providing psychoeducation. While providing group therapy or peer support was not the initial intention of the OPES discussion board, this could be an avenue worthy of further development.

Motivations to complete the OPES program. This investigation revealed common characteristics that contributed to these women’s successful completion of the OPES program. These included a sense of responsibility and altruism, a willingness to go beyond their comfort zones, and having supportive and satisfying long-term relationships with their spouses/ partners. The implication these findings have for the types of people who sign up for and complete these online programs will be discussed, as well as for whom these groups might be best suited. Given these findings, recommendations will also be made for future recruitment and program development.

According to the results of this study, the types of people who sign up for and complete these types of online interventions are responsible/ reliable people who are committed to following through on their commitments. Their dedication to contributing something of themselves to scientific research, such as participating in the OPES study, in the hope that in doing so they could not only help themselves but other cancer survivors, appeared to serve as a strong motivating factor to complete the program and fulfill their commitments. These personal characteristics and values have been found to be particularly influential motivating factors among participants who feel they are not gaining much personal benefit from the intervention to actually complete these types of intervention programs (Donkin & Glozier, 2012).

This study’s findings also suggest that participants who possess a certain degree of willingness to go beyond their comfort zones in order to try and improve their sexual lives may

be more inclined to participate in and complete these types of intervention programs. Although there is no known research to support this claim, it is possible that those who can tolerate a certain degree of discomfort to try sexually-oriented activities may derive more benefit from these interventions than those less willing, ready or able to take such personal risks. For example, those women who can surpass social and generational conventions to go out, buy a vibrator, and introduce this into their relationships' sexual repertoire may not be typical of the majority of participants in these "self-help" programs. It is also important to bear in mind that participant willingness to work through discomfort in order to complete certain program exercises may be related to their dedication to meeting research expectations rather than for their own personal interest or benefit (Donkin & Glozier, 2012).

One significant finding in this study was that the support, encouragement and positive feedback that the participants' partners provided was very important in maintaining these participants' engagement in the OPES program. This is consistent with research that found women who had high relationship satisfaction and emotional intimacy with their partners were more likely to complete an online treatment program for female sexual dysfunction compared to women with poor relationship satisfaction or emotional bonding (McCabe & Jones, 2013). These findings corroborate a large body of research that has found partner support to be extremely important for psychosexual adjustment in the aftermath of cancer and its treatment (Altschuler et al., 2009; Gilbert, Ussher, & Perz, 2010; Juraskova et al., 2003; Manne & Badr, 2008) as well as having a satisfying sexual relationship prior to cancer and its treatment (Tierney, 2008). Relationship satisfaction has been found to be associated with intervention effectiveness in improving women's sexual functioning (Schover et al., 2011). Brotto and colleagues (2008) also discussed how their results suggested that partner cooperation and support may have impacted

women's progress and success with the face-to-face PED. Given this evidence, interventions such as the OPES programs may be best suited for people in well-functioning and supportive relationships, whether or not partners choose to actively participate in the intervention. Taken together, it is recommended that screening interviews for such interventions assess participants' quality of relationship functioning. Additional therapeutic support (i.e., individual and/or couples counselling) could be offered to participants who report relationship difficulties that would likely impact their participation. Considering the significant influence of partner's support, future development of the OPES program could include partners, although this should not be a requirement to program enrolment. Again, assessing the physical, psychological and relational needs of participants and meeting participants where they are is likely to increase participants' engagement with, motivation to complete, and perceived benefit gained from such programs.

In sum, the findings from this narrative inquiry have not only been valuable in providing deeper insight into the perceived benefits and challenges experienced by these participants, but also how the multilayered and interrelated aspects of their physical, psychological, behavioural, relational, environmental, and historical realities interacted in complex ways to influence their participation in and completion of the program. The qualitative results in this research deepen our understanding of how the OPES program was perceived and experienced as helpful, or not, for these participants who completed the program in a way that was not accessible through quantitative measures.

Implications for Future Research

As previously mentioned, the results of this narrative inquiry have been attained from an unrepresentative group of female participants who completed the OPES program and who were willing and eager to participate in this research study. As has also been brought up by Donkin

and Glozier (2012), it would be extremely useful to interview participants who do not complete interventions such as the OPES program. Learning more about their experiences with such programs and why these participants drop out would help inform the development of future programs that could meet a greater number of cancer patients and survivor's sexual health needs. There is also a need to conduct qualitative research with male survivors of colorectal cancer who completed the OPES program (and did not) or similar interventions, in order to learn more about the extent to which the current study's findings reflect their experiences. It would be useful to gain a deeper understanding into how gender and colorectal cancer, as well as the physical, psychological, and relational realities of these men, influence their engagement and experiences with such interventions as the OPES program.

Evidence suggests that the treatment of cancers that involve body parts not commonly associated with sexuality can have an equally negative impact on the physical, psychological and relational aspects of women's and men's sexual wellbeing (Tierney, 2008). The specific type of cancer the women in this study had did not seem to be as relevant to their participation in the OPES program as the profound impact the various treatments had on their ability to experience sexual pleasure and enjoy being sexually intimate with their partners. However, the vast majority of research on psychoeducational and psychologically-oriented interventions for sexual difficulties post-cancer continues to concentrate on patients and survivors of cancers that affect parts of the body that are directly associated with sexuality (i.e., reproductive and prostate cancers). Therefore, it is imperative and will likely be advantageous for this research to expand its inclusion criteria and make these programs available to patients and survivors of other types of cancers. In addition, although the OPES program only included participants who were in a

relationship, future research needs to specifically address the sexual health needs of single and dating people post-cancer and tailor interventions to meet their relational realities.

Sexual wellbeing and intimacy are complex, multilayered, and extremely personal phenomena. In addition, the degree of psychological, relational, and physical burden of a cancer diagnosis and its treatment varies greatly among individuals, as well as the length of time needed to recover. Considering these factors, including participants' goals and definitions of success in measuring the efficacy, acceptability and success of psychoeducational interventions for sexual wellbeing after cancer is a worthy avenue needing further exploration.

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Appendix A: Relevant Outcome Measures Used in Psychoeducational Interventions.

Study	Outcome Measures Used	Reference	Focus of Measure	Time Points
Ayaz and Kubilay (2009)	Golombok Rust Inventory of Sexual Satisfaction (GRISS)	Rust & Golombok (1986)	Assessed the sexual domains of erectile dysfunction, premature ejaculation, anorgasmia, vaginismus, noncommunication, infrequency, avoidance, nonsexuality, and dissatisfaction	<u>Intervention Group:</u> Pre-stoma, 6 weeks post-op and 4 month post-op <u>Control Group:</u> Pre-stoma and 4 months post-op.
	PLISSIT Model (not manualized)	Annon (1981)	The PLISSIT model (permission, limited information, specific skills, and intensive therapy) was used to guide assessment of patient's sexual problems	
Brotto et al. (2008)	Detailed Assessment of Sexual Arousal (DASA)	Basson & Brotto (2001)	Significantly differentiates aspects of sexual arousal in women; includes subscales such as "Mental excitement," "Genital tingling," and "Pleasant genital tingling"	Pre-intervention and 3 months post-intervention
	Female Sexual Distress Scale (FSDS)	Derogatis, Rosen, Leiblum, Burnett, & Heiman (2002)	Assessed levels of sexually-related distress	

Study	Outcome Measures Used	Reference	Focus of Measure	Time Points
Brotto et al. (2008)	Female Sexual Functioning Index (FSFI)	Rosen et al., (2000)	Assessed sexual domains of desire, arousal, orgasm, lubrication, satisfaction, and pain over last 4 weeks	Pre-intervention and 3 months post-intervention
	Sexual Function Questionnaire (SFQ); Treatment impact subscale	Adams et al. (1996)	Assessed sexual function specifically in cancer patients	
	Beck Depression Inventory (BDI)	Beck & Beamesderfer (1974)	Assessed depressive symptoms	
	Dyadic Adjustment Scale (DAS)	Spanier (1976)	Assessed relationship satisfaction	
	SF-36 Quality of Life Questionnaire (SF-36); Physical and Mental Component subscores	Ware & Sherbourne (1992)	Measured quality of life	
	Film Scale	Heiman & Rowland (1983)	Assessed <i>subjective</i> sexual arousal, perception of genital arousal, autonomic arousal, as well as anxiety, positive and negative affect during the physiological sexual-arousal assessment	

Study	Outcome Measures Used	Reference	Focus of Measure	Time Points
Brotto et al. (2012)	Female Sexual Functioning Index (FSFI)	Rosen et al. (2000)	Assessed sexual domains of desire, arousal, orgasm, lubrication, satisfaction, and pain over last 4 weeks	Pre-intervention post-intervention and 6-months follow-up
	Female Distress Scale (FSDS)	Derogatis et al. (2002)	Assessed levels of sexually-related distress	
	Beck Depression Inventory (BDI)	Beck & Beamesderfer (1974)	Assessed depressive symptoms	
	Sexual Function Questionnaire (SFQ); Treatment Impact and Relationship subscales	Adams et al. (1996)	Measured sexual functioning specifically for cancer survivors	
	Film Scale	Heiman & Rowland (1983)	Assessed <i>subjective</i> sexual arousal, perception of genital arousal, autonomic arousal, as well as anxiety, positive and negative affect during the physiological sexual-arousal assessment	

Study	Outcome Measures Used	Reference	Focus of Measure	Time Points
Brotto, Dunkley, Breckon, Carter, Brown, & Miller (2015) (manuscript submitted)	International Index of Erectile Function (IIEF)	Rosen et al. (2002)	Measured self-reported male sexual function “over the past four weeks” in the domains of erectile function, orgasm, desire, intercourse satisfaction, and overall satisfaction	Pre- and post-intervention, and 6 month follow-up
	Dyadic Adjustment Scale (DAS)	Spanier (1976)	Assessed relationship adjustment and satisfaction	
	Female/Male Sexual Distress Scale (FSDS/MSDS)	Derogatis et al., (2002)	<p>Assessed sexually-related distress (an important domain not assessed by the FSFI or other commonly used sexual functioning measures)</p> <p>A modified version of the FDS the MDS was used to measure sexually-related distress in men</p>	
	Beck Depression Inventory (BDI)	Beck & Beamesderfer (1974)	Assessed depression which is a common side effect and complicating factor of both cancer and sexual dysfunction	

Study	Outcome Measures Used	Reference	Focus of Measure	Time Points
Caldwell et al. (2003)	Changes in Sexual Functioning Questionnaire (CSFQ)	Clayton, McGarvey, & Clavet (1996); Clayton, McGarvey, & Clavet (1997)	Assessed changes in sexual desire, sexual activity and sexual satisfaction because of illness and medication (measures subscales of desire/ frequency, desire/ interest, pleasure/ enjoyment, arousal/ excitement, and orgasm)	Pre-intervention, post-intervention and 3-month follow-up
	Profile of Mood States (POMS)	McNair, Lorr, & Droppleman (1992)	Assessed affective states (tension-anxiety, depression-dejection, anger-hostility, vigor, fatigue-inertia, and confusion-bewilderment)	
Capone, Good, Westie, & Jacobson (1980)	The Self-Rating Symptom Scale	Williams et al. (1968)	Assessed symptoms of psychological distress among 5 factors: depression, fear-anxiety, performance difficulty, somatization, general neurotic feelings, and 3 clinical clusters (anxiety, depression, and anger-hostility)	Prior to primary cancer treatment, and 3, 6, and 12-month post-cancer treatment

Study	Outcome Measures Used	Reference	Focus of Measure	Time Points
Capone, Good, Westie, & Jacobson (1980)	The Profile of Mood States (POMS)	McNair et al. (1971)	Identified and assessed fluctuating and transient affective states among 6 factors: tension-anxiety, depression-dejection, anger-hostility, vigor, fatigue-inertia, and confusion-bewilderment	Prior to primary cancer treatment, and 3, 6, and 12-month post-cancer treatment
	Frequency of Intercourse	Research Team	Assessed sexual functioning	
Classen et al., (2013)	Female Sexual Distress Scale-Revised (FSDS-R)	Derogatis et al. (2002)	Assessed levels of sexually-related distress	Pre-intervention, after the immediate treatment group was completed (4 month follow-up), and a final assessment after the WL condition completed the intervention
	Hospital Anxiety and Depression Scale (HADS)	Zigmond & Snaith (1983)	Assessed the presence and severity of depression and anxiety in medical settings	
	The Illness Intrusiveness Rating Scale (IIRS)	Devins et al. (1983)	Assessed the extent to which cancer and/or its treatment interferes with life domains central to QoL (relationships and personal development, intimacy, and instrumental)	
	GyneGals Exit Questionnaire	The Research Team	21 items assessed satisfaction with program and support group	

Study	Outcome Measures Used	Reference	Focus of Measure	Time Points
Ganz, Greendale, Petersen, Zibecchi, Kahn, & Belin (2000)	Breast Cancer Prevention Trial Symptom Checklist; Menopausal Symptom Scale Score	Ganz, Day, Ware, Redmond, & Fisher (1995)	Assessed selected menopausal symptoms via 3 subscales: hot flashes, vaginal symptoms, and urinary symptoms	Pre-intervention and post-intervention (4-month follow-up)
	RAND 36-Item Health Survey 1.0 (also known as the Medical Outcomes Study SF-36); Vitality Scale	Ware & Sherbourne (1992); Hays, Sherbourne, & Mazel (1993)	Assessed health-related quality of life	
	Cancer Rehabilitation Evaluation System (CARES); Sexual Summary Scale	Schag, Heinrich, Aadland, & Ganz (1990); Ganz, Desmond, Belin, Meyerowitz, & Rowland (1999)	Assessed QOL and rehabilitation needs of cancer patients. The Sexual Summary Scales assessed sexual attractiveness for self and partner, interest in sex for self and partner, frequency of sex, arousal, lubrication, and orgasm	

Study	Outcome Measures Used	Reference	Focus of Measure	Time Points
Jeffries, Robinson, Craighead, & Keats (2006)	Multiple-choice questionnaire and interviews on frequency of vaginal dilation and patterns of dilator use	Research Team	Assessed compliance with vaginal dilation, and patterns of use	Questionnaires at pre-intervention; and 6 week, 6-, 12-, 18- and 24-months post-intervention Interviews at 6-, 12-, 18-, and 24-months post-intervention
Marcus et al. (2010)	Impact of Event Scale (IES); Intrusion subscale	Horowitz, Wilner, & Alvez (1979); Sundin & Horowitz (2002)	Assessed the frequency of intrusive or distracting thoughts as a marker of distress	Pre-intervention and 3-, 6-, and 12-, and 18-months post-enrolment
	Center for Epidemiologic Studies Depression Scale (CES-D)	Radloff (1977)	Assessed depression	
	The Sexual Dysfunction Scale (Several items were developed specifically for this research)	Research Team; Wenzel et al. (1999)	Assessed 3 domains of sexual functioning: 1) <i>Behavioural</i> (i.e., pain with intercourse, frequency of sexually intimate behaviors); 2) <i>Evaluative</i> (included items assessing sexual interest, arousal, satisfaction); and 3) <i>Body Image</i> (i.e., global sense of attractiveness, impact of weight gain and hair loss)	

Study	Outcome Measures Used	Reference	Focus of Measure	Time Points
Maughan & Clark (2001)	European Organization for Research and Treatment of Cancer (EORTC) QLQ-C30	Osoba (1991); EORTC (1993)	Assessed the impact of breast cancer on woman's functional, psychological and social health	Pre-surgery and at 6-, 12-, and 24- weeks post-surgery
	Lasry Sexual Functioning Scale for Breast Cancer Patients	Lasry (1991)	Assessed sexual functioning and altered body image	
Reese, Porter, Somers, & Keefe (2012)	Index of Sexual Satisfaction	Hudson, Harrison, & Crosscup (1981)	Assessed sexual distress (e.g., "I try to avoid sexual contact with my partner")	Pre- and post-intervention
	Female Sexual Functioning Index (FSFI)	Rosen et al. (2000)	Assessed sexual domains of desire, arousal, orgasm, lubrication, satisfaction, and pain over last 4 weeks	
	International Index of Erectile Functioning (IIEF)	Rosen et al. (1997)	Measured self-reported male sexual function "over the past four weeks" in the domains of erectile function, orgasm, desire, intercourse satisfaction, and overall satisfaction	

Study	Outcome Measures Used	Reference	Focus of Measure	Time Points
Reese, Porter, Somers, & Keefe (2012)	Dyadic Sexual Communication Scale	Catania (1986)	Assessed perceived quality of communication about sex in intimate relationships (e.g., “My partner and I can usually talk calmly about our sex life”)	Pre- and post-intervention
	Miller Social Intimacy Scale	Miller & Lefcourt (1982)	Assessed the degree of emotional intimacy, trust and closeness towards an intimate partner (e.g., “How often do you confide very personal information to him/her?”).	
	4-Item Dyadic Adjustment Scale of the 32-item Dyadic Adjustment Scale	Sabourin, Valois, & Lussier (2005). The 4-item scale was constructed by the research team using a nonparametric analysis of the 32-item DAS	Assessed degree of dyadic adjustment	

Study	Outcome Measures Used	Reference	Focus of Measure	Time Points
Reese et al. (2014)	Index of Sexual Satisfaction	Hudson et al. (1981)	Assessed sexual distress (e.g., “I try to avoid sexual contact with my partner”)	Pre-intervention and post-intervention
	Dyadic Sexual Communication Scale	Catania (1986)	Assessed perceived quality of communication about sex in intimate relationships	
	Miller Social Intimacy Scale	Miller & Lefcourt (1982)	Assessed the degree of emotional intimacy, trust and closeness towards an intimate partner	
	Female Sexual Functioning Index (FSFI)	Rosen et al. (2000)	Assessed sexual domains of desire, arousal, orgasm, lubrication, satisfaction, and pain over last 4 weeks	

Study	Outcome Measures Used	Reference	Focus of Measure	Time Points
Reese et al. (2014)	International Index of Erectile Functioning (IIEF)	Rosen et al. (1997)	Measured self-reported male sexual function “over the past four weeks” in the domains of erectile function, orgasm, desire, intercourse satisfaction, and overall satisfaction	Pre-intervention and post-intervention
	Sexual Function Questionnaire; Medical Impact subscale	Syrjala et al. (2000)	Assessed the impact of colorectal cancer and its treatment on participants sexual function and adjustment to sexual difficulties	
	Sexual Self-Efficacy Scale (designed for this study)	Research Team	Assessed level of confidence in communicating effectively about issues related to physical intimacy/sex; dealing effectively with sexual difficulties; and enjoying intimacy despite physical limitations	
	Rates of study enrolment and participation and post-treatment program rating scale	Research Team	Assessed program feasibility and acceptability (e.g., ease of participation, program helpfulness and importance, information relevance, level of rapport with therapist, skill utilization, skill helpfulness)	

Study	Outcome Measures Used	Reference	Focus of Measure	Time Points
Robinson, Faris, & Scott (1999)	Sexual History Form (SHF)	Nowinski & Lopiccolo (1979); Creti et al. (1998)	Assessed frequency of a variety of sexual activities, frequency of desire, subjective arousal, ability to reach orgasm with different types of stimulation, and dyspareunia	Pre-intervention and again at 3, 6, 9, and 12 months post-diagnosis
	Sexual Knowledge Questionnaire	Robinson, Scott, & Faris (1994)	Assessed level of knowledge thought to be necessary for the successful adjustment of gynaecological cancer patients	
	Fears about Cancer and Sexuality	Schover, Fife, & Gershenson (1989)	Assessed the extent to which different issues about cancer and sexuality have been a source of upset and worry	
	Vaginal dilation compliance self-report questionnaire	Research Team	Assessed compliance with recommendations for vaginal dilation (defined as using a dilator or having sexual intercourse or some combination of the two at a frequency of 3 times or more per week)	

Study	Outcome Measures Used	Reference	Focus of Measure	Time Points
Robinson, Faris, & Scott (1999)	Sex History Form (one question)	Research Team	Assessed frequency of sexual intercourse	Pre-intervention and again at 3, 6, 9, and 12 months post-diagnosis
	Profile of Mood States, short form (POMS-SF)	McNaire, Lorr, & Droppleman (1971); Shacham (1983)	Assessed mood disturbance	
	Dyadic Adjustment Inventory	Spanier (1976)	Assessed relationship happiness	
Rowland et al., (2009)	Revised Dyadic Adjustment Scale (RDAS)	Busby, Crane, Larson, & Christensen (1995); Spanier (1976);	Assessed relationship functioning and overall relationship adjustment (e.g., satisfaction, consensus and cohesion)	Baseline (from the preliminary survey used to identify eligible participants) and 4 months post-intervention
	32-item Mental Health Index (MHI-32)	Sherbourne (1992)	Assessed mental health (anxiety, depression, loneliness, distress, wellbeing and positive affect)	
	10 Sexual Outcome Likert-scaled items	Research Team	Assessed self-report levels of sexual satisfaction, sexual pain, comfort with sexual situations, overall subjective impact of breast cancer on sexuality, and the degree to which communication with their partner had improved since baseline	

Study	Outcome Measures Used	Reference	Focus of Measure	Time Points
Schover, Jenkins, Sui, Adams, Marion, & Jackson (2006)	Functional Assessment of Chronic Illness Therapy; 12-Item Spiritual Well Being Subscale (FACIT-Sp-12)	Peterman, Fitchett, Brady, Hernandez, & Cella (2002)	Assessed spiritual wellbeing	Pre-intervention, after waitlist period, post-intervention, and 3 months post-intervention
	Female Sexual Functioning Index (FSFI)	Wiegel, Meston, & Rosen (2005)	Assessed sexual domains of desire, arousal, orgasm, lubrication, satisfaction, and pain over the last 4 weeks	
	Breast Cancer Prevention Trial (BCPT) Menopause Symptom Checklist; 7 items that form three subscales: urinary incontinence, vaginal irritation, and hot flashes)	Ganz, Rowland, Desmond, Meyerowitz, & Wyatt (1998); Ganz et al. (2000)	Assessed bother menopausal symptoms: urinary incontinence, vaginal irritation, and hot flashes	
	Brief Symptom Inventory-18 (BSI-18)	Zabora et al. (2001)	Assessed emotional distress such as depression and anxiety	

Study	Outcome Measures Used	Reference	Focus of Measure	Time Points
Schover, Jenkins, Sui, Adams, Marion, & Jackson (2006)	Abbreviated form of the Dyadic Adjustment Scale *for women who were in a committed relationship	Sharpley & Cross (1982); Hunsley, Pinsent, Lefebvre, James-Tanner, & Vito (1995)	Assessed relationship satisfaction for partnered participants	Pre-intervention, after waitlist period, post-intervention, and 3 months post-intervention
	Cancer Rehabilitation Evaluations System (CARES); <i>Dating</i> subscale *for single women	Schag et al. (1990)	Assessed comfort in dating after cancer for single participants	
	A 25-item true/false knowledge test on the basis of the workbook	Research Team	Assessed knowledge acquisition from the SPIRIT workbook material	
Schover et al. (2011)	Functional Assessment of Cancer; 12-Item Spiritual Well Being Subscale (FACIT-Sp-12)	Peterman et al. (2002)	Assessed spiritual wellbeing	Pre-intervention post-intervention and 6-, 12-months post-intervention

Study	Outcome Measures Used	Reference	Focus of Measure	Time Points
Schover et al. (2011)	Abbreviated form of the Dyadic Adjustment Scale (A-DAS) *for women who were in a committed relationship \geq 6 months	Hunsley et al. (1995); Sharpley & Cross (1982)	Assessed relationship satisfaction for partnered participants	Pre-intervention post-intervention and 6-, 12-months post-intervention
	Cancer Rehabilitation Evaluations System (CARES); <i>Dating</i> subscale *for single women	Schag et al. (1990)	Assessed comfort in dating after cancer for single participants	
	Brief Symptom Inventory-18 (BSI-18)	Zabora et al. (2001)	Assessed emotional distress such as depression and anxiety with a Global Severity Index (GSI) summary score	
	Female Sexual Functioning Index (FSFI)	Wiegel et al. (2005)	Assessed sexual domains of desire, arousal, orgasm, lubrication, satisfaction, and pain over the last 4 weeks	

Study	Outcome Measures Used	Reference	Focus of Measure	Time Points
Schover et al. (2011)	Breast Cancer Prevention Trial (BCPT) Menopause Symptom Checklist; 7 items that form three subscales: Urinary Incontinence, Vaginal Irritation, and Hot Flashes	Ganz et al. (2000)	Assessed bother menopausal symptoms	Pre-intervention post-intervention and 6-, 12-months post-intervention
	A 25-item true/false knowledge test	Research Team	Assessed knowledge acquisition from the SPIRIT workbook material	
	Program Evaluation Questionnaire	Research Team	Anonymous participant evaluations	
Schover, Yuan, Fellman, Odensky, Lewis, & Martinetti (2013)	Female Sexual Functioning Index (FSFI)	Wiegel et al. (2005); Baser, Li, & Carter (2012)	Assessed sexual domains of desire, arousal, orgasm, lubrication, satisfaction, and pain over last 4 weeks	Pre-intervention, post-intervention and at 3- and 6-month follow-up

Study	Outcome Measures Used	Reference	Focus of Measure	Time Points
Schover, Yuan, Fellman, Odensky, Lewis, & Martinetti (2013)	Menopausal Sexual Interest Questionnaire (MSQ)	Rosen, Lobo, Block, Yang, & Zipfel (2004)	Assessed sexual interest through desire, pleasure, orgasm, and satisfaction subscales	Pre-intervention, post-intervention and at 3- and 6-month follow-up
	Brief Symptom Inventory-18 (BSI-18)	Zabora et al. (2001)	Assessed emotional distress such as depression and anxiety with a Global Severity Index (GSI) summary score	
	Quality of Life in Adult Cancer Survivors (QLACS)	Avis et al. (2005); Avis, Ip, & Foley (2006)	Assessed global quality of life	
	12-Item Likert-scaled program evaluation	Research Team	Anonymously assessed evaluations participants had of intervention	

Appendix B: The OPES Program

Participants in OPES would log onto the password protected website to access each module's material which included written information and/or pictures, graphs, audio recordings and written or experiential exercises. All material was identical for men and women, and gender-specific content was described separately for men and women (e.g., definition of arousal discussed both erection for men and vaginal vasocongestion for women). Participants were instructed to enter their responses to exercises and any feedback/ experiences they had with the module and homework exercises in appropriate spaces provided on the website.

The Title and Content of Each Module:

- 1) Importance of Sexuality, Definitions of Sexual Desire and Arousal, and Sexual Difficulties with Cancer and Its Treatment.
 - How important is sexuality to your quality of life? Invites participant self-reflection on this topic and includes exercises to complete on the website
 - Includes definitions of sexual desire and arousal and provides description/graph of Sexual Response Cycle (Basson, 2002)
 - Homework included thinking about and responding about own incentives/ motivations for being sexual
 - Information on the prevalence of sexual difficulties following gynaecological and colorectal cancer and treatment
- 2) Predisposing, Precipitating, Perpetuating, & Protective Factors
 - Explanation of what are predisposing, precipitating, and perpetuating factors, as well as protective factors, in his/her sexual difficulties and curette experience of sexuality.
 - Homework included filling out a schematic of these factors on the website

3) Sexual Beliefs.

- Common sexual beliefs/ irrational thoughts/ myths and their impact on sexual function and satisfaction
- Homework included thinking about own sexual beliefs and recording them in space provided on the website

4) Mindfulness.

- Introduction to mindfulness and its applications to sexuality
- Mindfulness meditation audio-clip: Mindfulness to your senses
- Homework included repeating meditation everyday for following week and recoding how “present” you were during the practice (on the website)

5) Genitals and Kegel Exercises

- Education on female and male genital anatomy and physiology and its role in sexual response
- Instruction on a genital self-exploration exercise
- Explanation of Kegel exercises and its importance for both genders
- Instruction on how to do Kegel exercises

6) Body Image.

- Discussion of body image and how it may be related to sexuality
- Instruction on a focusing exercises
- Homework included recording reactions to the focusing exercise (positive and negative)

7) Relationship Satisfaction and Communication.

- Discussion of importance of relationship variables in sexual health

- Reflection exercises on valuable and problematic aspects of relationship (to be recorded on the website)
- Homework included choosing one of several topics of discussion to have with your intimate partner

8) Self-observation and Touch.

- Instruction on body-oriented mindfulness exercises (focusing and self-observation)
- Instruction on self-sensate focus exercise and partner-sensate focus exercise
- Progressive muscle relaxation exercise

9) Thought Records.

- Introduction to cognitive-behavioural therapy and instructions on using thought records.
- Homework included tracking automatic thoughts for one week and completing thought record on the website

10) Mindfulness Thought Stream & Body Scan.

- Instruction on mindfulness of sounds and thoughts meditation
- Instruction on full body scan
- Homework included completing another full body scan over the week and note reactions on the website

11) Sexual Aids to Boost Arousal.

- Introduction to using sexual aids such as erotica, fantasy, and vibrators/ stimulators to enhance sexual arousal and pairing it with mindfulness

12) Moving On and Non-Psychological Interventions.

- Discussion of how to move on from the OPES program in order to maintain one's

gains, including how to anticipate barriers to continued use of the skills and exercises learned in the program.

The Online Discussion Board

In addition to the weekly modules, all participants had access to a moderated and password-protected bulletin board on the OPES website where they could post questions under a selected alias and the PI and/or research coordinator would respond. Participants only had access to those questions relevant to material that they had already covered (and not to questions relating to a future module). It was hoped that this feature of the program would introduce a minimally interactive component and provide an opportunity for participants to learn from the experiences of others. Throughout the study, the discussion board was used infrequently and not by all participants. Participant posting of questions, comments, technical difficulties, feedback, and responses to posts made by the coordinator declined as modules progressed (i.e., there was a total of 63 individual posts made by participants over all the module bulletin boards with more posts made in modules 1-6 (41 posts) compared to the later half (20 posts).

Appendix C: Invitation Email



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THE UNIVERSITY OF BRITISH COLUMBIA

Faculty of Education Vancouver Campus
Educational & Counselling Psychology,
And Special Education
2125 Main Mall
Vancouver, B.C. Canada V6T 1Z4

Phone 604-822-0242
Fax 604-822-3302
www.ecps.educ.ubc.ca



BC Cancer Agency
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PARTICIPANT RECRUITMENT CONFIRMATION

Online Psychoeducation for Sexual Dysfunction in Cancer Survivors_Qualitative Interviews

Email Subject Line: OPES Study Follow-up

Email Body:

Dear [name],

Once again thank-you for the time and effort you put into participating in the OPES Study. We have completed our study and are now seeking to gain a more in-depth understanding of participants' experiences of participating in, and completing the OPES program. In a follow-up phone call after you finished the program with the OPES research coordinator, Erin Breckon, you indicated an interest in participating in an in-depth follow-up interview about your experience of the OPES program. This letter is an invitation for you to participate in this research study about your experiences of participating and completing the OPES program by the UBC Departments of Obstetrics and Gynaecology and Counselling Psychology and the Vancouver Cancer Centre of the BC Cancer Agency (BCAA).

This new aspect of the OPES study will be conducted by Erin Breckon, under the supervision of myself, the OPES Principal Investigator, and her thesis supervisor, Dr. Judith Daniluk in order to fulfill the requirements for her Master's degree in Counselling Psychology at UBC.

We are interested in participants' experiences, both positive and negative, in working through and completing the tasks and exercises in program. The purpose of these interviews is to add to the quantitative study data, by gaining a more in-depth and comprehensive understanding of what it was like doing the modules. There was a significant drop out rate during this program, and many participants took much longer to complete the program than was originally expected. That said, if we are to make the OPES program as effective and user-friendly as possible, it is important to gain a better understanding of the challenges and benefits that participants' experienced throughout the program. We are keen to learn about what motivated individuals to participate in, and complete the program.

Participating in this follow-up study would involve: one confidential, in-depth and audio-recorded interview with Erin of approximately 90 minutes, and a brief 30 – 60 minute follow-up interview

with her during which she will ask you to verify that the narrative she constructs from your story and the thematic analysis is an accurate reflection of your experience. Ideally, the interviews can take place at your home, a private space on the UBC Campus in the Department of Counselling Psychology or at the Diamond Health Care Centre at VGH, or another mutually agreed upon private location of your convenience. Alternately, if you are not living in the Greater Vancouver area or reside out of the Lower Mainland, we can arrange to do the interview face-to-face via a confidential Telemedicine platform called VSee (<http://vsee.com>).

In total, the time commitment would be approximately 2.5 hours. You would have the right to withdraw from this follow-up study at any time, without consequence. Your participation in this study is voluntary and confidential. You can choose not to answer questions which you are not comfortable answering during the interview.

Please contact Erin Breckon if you are still interested in being interviewed for this follow-up study. She will set up a convenient time to discuss the study over the phone, and will be able to answer any additional questions you might have, prior to making a commitment to participate. We look forward to hearing back from you at your earliest convenience. You can contact Erin Breckon via phone, or via e-mail.

This study is being conducted under the supervision of Dr. Judith Daniluk, Professor of Counselling Psychology at UBC, and Dr. Lori Brotto, Director of the UBC Sexual Health Laboratory and Associate Professor in the Department of Obstetrics and Gynaecology at UBC.

Overall, we hope that participating in this research will be a positive experience for you and an opportunity to share some of your significant experiences.

Sincerely,
Lori Brotto, PhD, R Psych

Department of Obstetrics and Gynaecology
University of British Columbia
Contact Number:
Email:

Appendix D: Informed Consent Form



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THE UNIVERSITY OF BRITISH COLUMBIA

Faculty of Education Vancouver Campus
Educational & Counselling Psychology,
And Special Education
2125 Main Mall
Vancouver, B.C. Canada V6T 1Z4

Phone 604-822-0242
Fax 604-822-3302
www.ecps.educ.ubc.ca



BC Cancer Agency

CARE & RESEARCH

Subject Information and Consent Form

Online Psychoeducation for Sexual Dysfunction in Cancer Survivors_Qualitative Interviews

Principal Investigators:
(Supervisors)

Lori Brotto, PhD, R Psych
Department of Obstetrics and Gynaecology
University of British Columbia
Contact Number:
Email:

Dr. Judith Daniluk, Professor
Department of Educational and Counselling Psychology
University of British Columbia
Contact Number:
Email:

Co-Investigator:

Erin Breckon, MA Student
Department of Educational and Counselling Psychology
University of British Columbia
Contact Number:
Email:

Contact:

Erin Breckon, Study Coordinator
UBC Sexual Health Laboratory
Telephone:
Email:

Non-Emergency contact numbers are noted at the end of this document under the section heading "Contact".

Your participation is voluntary

Your participation is entirely voluntary. It is up to you to decide whether or not to take part in this study. Before you decide, it is important for you to understand what the research involves. This consent form will tell you about the study, why the research is being done, what will happen to you during the study and the possible benefits, risks and discomforts.

If you do decide to take part in this study, you may withdraw at any time without giving reasons for your decision. If you do not wish to participate, you do not have to provide any reason for your decision not to participate.

Purpose

The research is being conducted in partial fulfillment of the requirements for a Master of Arts degree in Counselling Psychology from the University of British Columbia.

The purpose of this study is to gain a more in-depth and comprehensive understanding of men and women's experiences of working through the 12 module, OPES online psychoeducation intervention aimed at healing the sexual aftermath, following the diagnosis and treatment of colorectal, gynecological, or breast cancer.

An in-depth exploration of the experiences of individuals who completed the OPES program, will provide a deeper understanding of the changes in participants' sexual self-perceptions and experiences throughout, and following completion of the program. Important information will also be gained about some of the challenges experienced by participants in completing the tasks, exercises, and homework assignments required in the program. This information will inform us on how we can better meet the needs of women and men who have survived cancer and want to improve their sexual lives and relationships, in the aftermath of cancer treatment

Research Question

The following question will guide this inquiry: **How did women and men who completed the OPES online psychoeducational program for sexual difficulties after cancer treatment experience the program, and how did their sexual lives and relationships change throughout and following completion of the program.**

Who can participate in this study?

You may participate in this study if:

- You were eligible for and consented to participate in the OPES program
- You completed all 12 modules and all three research assessments of the OPES program
- You fully understand this study and give your informed consent to participate as demonstrated by signing this consent form
- You feel you are physically and emotionally able to participate in one 90 minute tape-recorded interview, and a 30 – 60 minute follow-up interview
- You agree to having the interview audio recorded

Study Procedures

This study will involve approximately 2.5 hours of your time:

1. The researcher will meet with you for one individual 90 minute tape-recorded interview and one follow-up interview at a mutually agreed upon location with the possibility of conducting interviews over VSee (<http://vsee.com>) for participants who live outside the Greater Vancouver area. You will have an opportunity to share your experiences of completing the OPES program.

Please note: VSee is a Telemedicine platform that is supported by the National Health Institutes of Health and has been approved by the Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy, Security and Breach Notification Rules for the use in confidential, medical situations. It is also free for you to download for basic use. Although the interview that will be conducted is non-medical and for research purposes, the researchers want to provide participants with the most secure environment that can be provided. It has been determined that VSee is a better alternative for internet-based research interviews compared to more common programs such as Skype or Facetime that are intended for consumer use only.

2. After transcription, analysis, and interpretation of the confidential interviews, the researcher will develop a narrative summary of each participant's story. You will be given written copies of both your individual narrative and the thematic analysis. Should you wish to receive this by email, the document will be attached as password protected and encrypted file and you will receive the password over the telephone.
3. The researcher will meet with you for a validation interview, approximately 30 to 60 minutes, to discuss the findings. You will have an opportunity to review the findings and your personal narrative summary to ensure that it resonates and reflects your experiences.

Risks

Although the utmost care and effort will be made to protect your confidentiality, this cannot be fully guaranteed when your individual narrative and thematic analysis are sent to you via conventional mail or email. In order to mitigate the potential risk that any sensitive information in your story be intercepted, study results can be received in-person from the researcher, delivered to you via courier mail requiring a signature, or through email as a password-protected and encrypted file. Passwords will only be given directly to you over the phone. These documents will not contain any personal identifying information.

Also, as with any work where people have the possibility of self-awareness and insight through remembering lived experience, there is always potential for feelings to come to light that might be stressful or uncomfortable. If you experience strong feelings during or after the interviews, you will be encouraged to speak to the researcher immediately or contact her by phone. The researcher will also provide you with a list of referral sources should you decide to seek professional support.

Benefits

Participating in this study may be a positive experience for you personally, in being able to reflect on the changes that have occurred for you as a consequence of completing the OPES program. It may also be beneficial to know that through your involvement in this study, you will provide the program developers with important feedback and information that can be used to improve the program so that it better meets the needs of cancer survivors.

Confidentiality

Any information resulting from this research will be kept strictly confidential, to the extent permitted by applicable laws and regulations. Your study records will *not* be publicly available. Both Dr. Judith Daniluk (supervisor) and Dr. Lori Brotto (principle investigator of the OPES program) and Erin Breckon (co-investigator) will have access to the raw data.

No information that discloses your identity will be released or published without your specific consent to the disclosure. All information associated with this study will be kept behind locked doors or in secure computer files. The audio-recording of your interview and transcript will be de-identified and assigned a code number which will be accessible only by the researchers in a secure computer file kept separate from your data. All transcribed interviews will be kept in a locked filing cabinet at the UBC Sexual Health Laboratory at the Diamond Health Care Centre. You will not be identified by the use of your own name or initials and your identity will be kept strictly confidential in any publication resulting from this research. The tape-recordings will be erased following the study's completion and transcripts will be kept in a locked cabinet or under a password in a computer hard drive at the UBC Sexual Health Lab, and destroyed after five years. You will be given written copies of both your individual narrative and the thematic analysis.

Compensation:

There will be no monetary compensation for your participation.

Remuneration:

The investigators conducting this study will not receive any personal payments for conducting this study. In addition, neither the BC Cancer Agency nor any of the investigators conducting this study will receive any direct financial benefit from conducting this study.

Contact for Information about the Study

You understand that if you have any questions or desire further information with respect to this study, or if you experience any adverse effects, you can speak to Dr. Lori Brotto, the Principal Investigator for the OPES study, or Dr. Judith Daniluk, my thesis supervisor, in the Department of Educational and Counselling Psychology.

Contact for Concerns about the Rights of Research Subjects:

If you have any concerns about your treatment or rights as a research participant you may contact the Research Subject Information Line at the UBC Office of Research Services at the University of British Columbia at (604)-822-8598, or toll free at 1-877-822-8598, or by email to: RSIL@ORS.ubc.ca.

Subject Consent

I have read the above information, and have had an opportunity to ask questions. I understand that my participation in this study is entirely voluntary. I may refuse to participate or withdraw at any time without negative consequences. I understand that I may ask questions about this study in the future. I will receive a signed copy of this consent form including all attachments, for my own records.

My signature below indicates that I consent to participate in this study.

Participant's Signature

Printed name

Date

Researcher's Signature

Printed name

Date

Appendix E: Orienting Statement & Interview Questions



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THE UNIVERSITY OF BRITISH COLUMBIA

Faculty of Education Vancouver Campus
Educational & Counselling Psychology,
And Special Education
2125 Main Mall
Vancouver, B.C. Canada V6T 1Z4

Phone 604-822-0242
Fax 604-822-3302
www.ecps.educ.ubc.ca



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ORIENTING STATEMENT & INTERVIEW QUESTIONS

Orienting Statement

I am interested in learning about your experiences of working through and completing the OPES program – an online 12 module psychoeducational intervention aimed at healing the sexual aftermath of colorectal, gynecological or breast cancer. The main question guiding this interview is: ***How did you experience the OPES online psychoeducational program for sexual difficulties after cancer treatment, and what changes did you experience in terms of your sexual life and relationship, during and following completion of the program?***

To help you begin to tell your story, please take a moment to consider what the experience of cancer and its impact on your sexual life has meant to you and how you experienced the OPES program in working through the sexual aftermath of cancer and its treatment. *I will ask the participant if they would like me to remind them of the subject matter contained in the 12 modules of the OPES program.*

Please feel free to take as much time as you need to reflect on, and answer this question. I am not going to ask you a series of questions. Instead, I hope to encourage you to speak freely about your experiences. Considering the sensitive nature of this topic, I will leave it to your discretion and level of comfort, to determine how much detail you wish to share with me. On the other hand, during the interview I may ask you if you can elaborate on or clarify something you've said so that I can more fully understand your experiences. You are not obligated to answer any questions or discuss anything you are not comfortable with. Do you have any questions before we begin?"

General Research Question

"How did you experience the OPES online psychoeducational program for sexual difficulties after cancer treatment, and what changes did you experience in terms of your sexual life and relationship, during and following completion of the program?"

Open-ended Probing Questions

Throughout the interview, I may ask questions or use statements or probes to help increase the depth of the interview, such as:

1. Could you please tell me more about how that (information, exercise, moment, awareness, realization, insight, etc.) was for you?
2. Can you tell me more about what that experience meant to you?
3. How was that (information, exercise, realization) significant for you?
4. What were your thoughts and feelings during that (experience, module, exercise, conversation with your partner)?
5. What do you mean by...?
6. How do you think going through the OPES program changed your sexual self-perceptions? What about your sexual well-being?
7. How has the program influenced your relationship with your partner?
8. What were the challenges you experienced in completing the OPES program? When you bumped up against these challenges, how did you overcome them?
9. What were the benefits you experienced in completing the program?
10. What motivated you to complete the program?
11. Is there anything else you would like to add about that?
12. What would have been helpful for you in improving your experience with the OPES program?
13. What do you think it takes for men/ women to heal sexually after cancer and its treatment?
14. If you were speaking to someone who is experiencing sexual difficulties after colorectal, gynecological or breast cancer, what advice would you give them?
15. What advice would you like to give to health care providers treating people for gynecological, colorectal or breast cancer?
16. What specific feedback would you like to give to the developers of the OPES program, about the content or delivery of the program, or the support available to participants as they work through the program?

When the participant has indicated that the story is finished, I will ask if there is anything further he or she would like to add.

Appendix F: Closing Comments

I want to thank-you for your time and participation in this interview. How was your experience of talking with me today? What questions do you have for me as we end our time together?

As for the next steps of this study, first I will transcribe our interview. If I find there is any identifying information in the transcript (i.e., yours or your husband's/ wife's name) I will delete this information to protect your confidentiality. My recording of our interview will be downloaded onto a password protected computer at VCH and then deleted from this recording device. Secondly, I will synthesize your story into a "narrative story" and explore what important themes or concepts came up in your story. I will be doing this for everyone I interview. Third, I will be comparing the content from everyone's stories for similar and dissimilar themes.

After this I will contact you again to send you my findings, including a copy of our co-constructed narrative of your experience, and to schedule a half hour interview where I would like to review with you the study findings and to ensure they resonate and reflect your personal experiences. How does this sound?

Thank-you again for your time and I look forward to talking with you about the results and hearing your feedback.

Appendix G: Validation Interview



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Faculty of Education Vancouver Campus
Educational & Counselling Psychology,
And Special Education
2125 Main Mall
Vancouver, B.C. Canada V6T 1Z4

Phone 604-822-0242
Fax 604-822-3302
www.ecps.educ.ubc.ca

VALIDATION INTERVIEW GUIDE QUESTIONS

Guide Questions for Individual Narrative Validation Interview with Participants

The purpose of this interview is to review your personal narrative that I have written based on the material from our earlier tape-recorded interview. During the past two weeks, you have had the opportunity to read and review this narrative. I would like you to consider the following questions:

1. Coherence - Is your story coherent? Are the findings understandable? Is there anything missing from your story – anything that you would like to add or change?
2. Comprehensiveness – Overall, is your story comprehensive? Are there enough details and content?
3. Resonance – Is the narrative an accurate reflection of your experience of completing the OPES online psychoeducational program for sexual difficulties after cancer treatment? Does it adequately capture the meaning your participation had for you as sexual being after cancer?
4. Pragmatic – If your participation in the study provided you with new insights and/or enhanced your life in any way, how did it do so? How do you think your story might influence/help others who have been treated for gynecological, colorectal or breast cancer?

Guide Questions for Common Themes Narrative Validation Interview with Participants

The purpose of this interview is for you to review the common themes narrative that I have written based on the common themes across all six individual narratives. During the past two weeks, you have had the opportunity to read and review this narrative. I would like you to consider the following questions:

1. Coherence - Is the common narrative coherent? Are the findings understandable?
2. Comprehensiveness – Overall, is the story comprehensive? Are there enough details and content?
3. Resonance – Is the common narrative an accurate reflection of your experience of completing the OPES online psychoeducational program for sexual difficulties after cancer treatment? Does it adequately capture the meaning your participation had for you as sexual being after cancer?

4. Pragmatic – If your participation in the study provided you with new insights and/or enhanced your life in any way, how did it do so? How do you think the common story might influence/help others who have been treated for gynecological, colorectal or breast cancer?

Appendix H: Community Resources

1) Bianca Rucker, RN, RMFT, Ph.D.

Telephone: 604-731-4466

Website/ Email: www.biancarucker.com

2) Yvonne Erskine, M.Ed., RCC

Telephone: 604-809-1019

Email: Yvonne.Erskine@vch.ca

3) Kelly Smith, Ph.D.

Telephone: 604-786-0285

Email: Kelly.Smith@vch.ca

4) Jason Winters, Ph.D.

Telephone: 778-233-5449

Email: djpwinters@gmail.com

5) David McKenzie, Ph.D., RCC, AASECT, ACS

Telephone: 604-813-6047

Website/ Email: <http://www.davidmckenzie.ca/>

6) BC Association of Clinical Counsellors

Telephone (local to Victoria): 250-595-4448

Toll Free in Canada: 1 (800) 909-6303

Email: hoffice@bc-counsellors.org

Website: <http://bc-counsellors.org/>

7) BC Psychological Association

Telephone (local to Vancouver): 604-730-0522

Toll Free: 1 (800) 730-0522

Website: <http://www.psychologists.bc.ca/>