

COUPLE SEXUALITY AFTER TREATMENT FOR COLORECTAL CANCER AND  
ADAPATION TO AN OSTOMY: BRIDGING THE DIVIDE BETWEEN NEEDS,  
RECOMMENDATIONS, AND TREATMENT

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## Abstract

**Objective:** Over the course of three sequential qualitative studies, this investigation aims to better understand and support couples' sexual adjustment following ostomy surgery for colorectal cancer (CRC).

**Method:** Study 1 consists of a grounded theory analysis of interviews with 11 couples about their sexual adjustment. Study 2 presents an embedded-case study of a novel online intervention to facilitate conversations within couples about the sexual changes they have experienced following the ostomy and CRC. The analysis uses post-treatment interview transcripts with two couples and facilitator observations as sources of data. Study 3 entails a thematic analysis of interviews with 11 healthcare providers (HCPs) about the barriers to engaging couples in a trial of the same online intervention, following challenges in recruitment.

**Results:** In study 1, results point to a natural resiliency of couples to adjust to sexual changes imposed by the ostomy and CRC, at least to some degree, and yet the need for HCPs to offer support to couples around these concerns. Results of study 2 reveal several avenues for future development of the program and provide preliminary information about the intervention's acceptability and feasibility. In study 3, results describe several barriers to recruitment at the level of the system, HCP, patient, and intervention.

**Discussion:** As a collection these studies underscore the complexity of the sexual health needs of this relatively underserved cancer population and their partners, while simultaneously offering a brief approach to intervention that may support these couples' sexual adjustment and shedding light on the barriers that need overcoming to conduct research in this area.

## DEDICATION

To my parents who sparked the psychologist in me by encouraging my curiosity about emotions from an early age. You have exemplified for me what it means to be a 'we' in the face of cancer, twice. Without you both, none of this would have been possible.

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## **Chapter 1**

### **Introduction**

Sexual health is largely ignored in oncology supportive care. Research demonstrates that, on average, 50-60% of cancer patients experience sexual concerns (Schover, 2019) and surveys of Canadian cancer patients demonstrate that changes in sexual function and worry about these changes are among their greatest concerns during their transition from treatment (Canadian Partnership Against Cancer, 2018). Despite the importance of sexual health concerns, not only has sexuality been identified as an unmet need in supportive care in Canada and other countries (Wang et al., 2018), it is also one of the least studied domains of unmet care (Harrison et al., 2009). Healthcare providers identify a lack of training in sexual health, a paucity of sexual health resources, time constraints, and discomfort with this sensitive topic as clinical barriers to engaging patients in sexual health care during cancer treatment (Averyt & Nishimoto, 2014; Maree & Fitch, 2019; Traa et al., 2014).

To date, researchers have largely focused on investigating the sexual changes experienced by patients with cancers located in sex or sexualized organs like breast, prostate, and gynecological cancers (Falk & Dizon, 2020; Gilbert et al., 2009; Maiorino et al., 2016). Accordingly, the majority of interventions to address sexual changes experienced by patients and their partners due to cancer have also been developed for and tested with couples belonging to these site groups (Badr & Krebs, 2013; Gilbert et al., 2009; Jonsdottir et al., 2018; Regan et al., 2012). Nevertheless, researchers who have studied the sexual impact of other cancers, including lung and colorectal cancers – the first and third most commonly diagnosed cancers in Canada respectively (Canadian Cancer Statistics Advisory Committee, 2019) – demonstrate that these patients similarly experience devastating physical and psychological challenges to their sexual

well-being in the wake of cancer (Behringer et al., 2013; Bober & Varela, 2012; Falk & Dizon, 2020; Katz & Dizon, 2016; Shell et al., 2008). Thus, patients with tumours in non-sexual or non-sexualized organs appear to be especially disadvantaged in terms the attention paid to sexual health within the current literature.

Among the understudied cancer sites, colorectal cancer (CRC) is distinct from most others by its treatment. In particular, patients with CRC may undergo colostomy or ileostomy surgery as part of their cancer treatment (Porter et al., 2014). Ostomies pose additional challenges to patients' sexual adjustment, introducing challenges to self-image, worry about leakage and appearance of the device, and fears about partners' reactions (Manderson, 2005; Ramirez et al., 2010; Sun et al., 2016; Vural et al., 2016). Despite the high disease burden of CRC relative to breast and prostate cancers – likely attributable, at least in part, to the challenges imposed by the ostomy (LeMasters et al., 2013) – CRC has received less than 6% of cancer research funds in Canada (Canadian Cancer Research Alliance, 2019a). Accordingly, relatively little research has been conducted with CRC patients about their sexual adjustment (e.g., Averyt & Nishimoto, 2014; Ramirez et al., 2010; Sun et al., 2016; Traa et al., 2012; Vural et al., 2016), and even fewer studies have included the perspective of partners (e.g., Çakmak et al., 2010; Ohlsson-Nevo et al., 2012; Persson et al., 2004; Silva et al., 2014; Traa et al., 2014) or gone as far as evaluating interventions to address these issues with couples (e.g., Ayaz & Kubilay, 2009; Reese et al., 2012, 2014). With high needs and little funding, patients and partners adjusting to the sexual impacts of CRC appear to be especially disadvantaged in benefiting from new research initiatives into their unique needs.

A 2016 report by Cancer Care Ontario on clinical care recommendations for sexual health in oncology appears to signal a socio-cultural shift within the province (and Canada more

broadly) to better integrate and more consistently address sexual health in cancer care. While several recommendations were put forth, including the provision of psychological supports for the majority of sexual concerns and inclusion of partners where possible, the authors called for health care providers to first and foremost initiate conversations with their patients about sexual health in the context of cancer (Barbera et al., 2016). While their recommendations were intended to be applied to all disease sites, they were based upon the current literature that overwhelming focuses on studies of breast and prostate cancer patients.

As a clinician-scientist in the field of psychosocial oncology, my research attempts to respond to the call to better address sexual health in cancer. In recognition of the great yet relatively understudied sexual health challenges of CRC patients, over the course of three sequential studies, I endeavoured to address the sexual health of this underserved group of patients and their partners. In the first study, I interviewed eleven couples about adjusting to life with a permanent colostomy and subsequently conducted a grounded theory analysis to identify and describe the profound psychosexual changes this subgroup of cancer patients and spouses experience – with one of the implications being the importance of psychosexual intervention to address this patient population’s unique needs. In turn, the second study involves my development and evaluation of a novel online intervention to begin to address the sexual health needs of couples living with a permanent ostomy after CRC. Based on emerging evidence, I designed this brief intervention to provide couples with an opportunity to have facilitated conversations about the sexual and intimate changes they have faced, with the aim of supporting their ability to navigate these changes together. Although intended as a pilot trial of the intervention, extreme challenges with recruitment made this original objective untenable. Therefore, out of necessity, I explored the intervention through an embedded-single case study

that uses post-treatment interviews and questionnaires from the only two couples that completed the intervention as well as my observations as the intervention facilitator as sources of data.

Lastly, in response to the low participant enrolment in the pilot trial of the intervention, I conducted a third study to elucidate barriers to recruitment by interviewing multidisciplinary health care providers who work with the intervention's target population. A resulting thematic analysis of these transcripts describes barriers at the level of the system, health care provider, patient, and intervention – from the perspective of eleven specialized health care providers – to engaging this particular patient population and their partners in supportive sexual health care and in the trial intervention in particular.

Together, the three studies raise questions about how researchers and medical and allied health care professionals can keep up with patients' demands for care as well as new standards and guidelines for clinical practice, when the infrastructure of the medical system does not necessarily support their ability to do so. At the same time, the studies are a reminder to researchers, clinicians and policy-makers alike that although patients identify challenges and unmet care needs in their treatment and recovery, their identification does not necessarily translate to seeking or accepting support or treatment for them (Fitch & Steele, 2010; Fitch & Maamoun, 2016). It is the hope that future endeavours to address sexual health within oncology, particularly those aiming to support CRC patients with ostomies, can learn from this work.

## **Gaps in Oncology Care**

### ***The Unmet Supportive Care Needs of Cancer Patients***

The most recent report on incidence of cancer published by the Canadian Cancer Society (CCS) estimated that 220,400 new diagnoses of cancer would be made in Canada in 2019 and that 63% of these individuals would be expected to survive beyond 5 years (Canadian Cancer

Statistics Advisory Committee, 2019). As medical interventions have advanced in oncology, and survivorship has steadily increased, the scope of patients' needs has evolved beyond curative life-saving treatments to include supportive care. Supportive care is defined as "provision of the necessary services for those living with or affected by cancer to meet their physical, emotional, social, psychological, informational, spiritual and practical needs during the diagnostic, treatment, and follow-up phases, encompassing issues of survivorship, palliative care and bereavement" (Fitch, 1994 as cited in Fitch, 2008, p. 11). Delivered via coordinated care between professionals (e.g., social work, psychology, palliative care, specialized nursing, family medicine, physiotherapy, nutrition, spiritual care) and volunteers (e.g., peer supporters) alike, supportive care encompasses all helping services beyond primary medical interventions (i.e., surgery, chemotherapy, and radiation) to support the quality of life of the patient and their family (Fitch, 2008).

Within cancer care specifically, patient needs assessments have revealed several areas of deficit. A systematic review of 50 studies that surveyed the unmet needs of advance stage cancer patients in Canada, the United States, the United Kingdom, Europe, Australia, and Asia using self-report needs assessment tools and semi-structured interviews, identified twelve domains of unmet patient needs: psychological, physical, health system and information, activities of daily living, social, financial, communication, spiritual, autonomy, sexuality, patient care and support, and nutrition (Wang et al., 2018). Of these, psychological (e.g., emotional support, uncertainty about the future), physical (e.g., fatigue, sleep problems, pain), and health system and information (e.g., information about treatment side effects) were the most commonly reported domains of unmet supportive care needs (Wang et al., 2018). An earlier systematic review of cancer patients' unmet needs at different stages of the cancer experience found variation in

similar domains of unmet needs across the disease trajectory; domains of activities of daily living, psychological, information, psychosocial, and physical were the most commonly reported overall (Harrison et al., 2009). The authors described a trend in the literature that suggested the levels of unmet needs are highest and most varied during treatment, but that a greater proportion of patients appear to experience unmet needs post-treatment and in survivorship compared to any other stage of the disease (Harrison et al., 2009). Geographic isolation from health services and limited social support were identified as predictors of higher unmet needs (Harrison et al., 2009) signaling a need for increased accessibility to services and connection to community. Notably, Harrison et al. (2009) also found that unmet needs related to communication, spirituality, and sexuality were the least investigated in the literature. Their finding points to a relative paucity of attention paid to these concerns in particular and suggests that unmet needs in these domains may be under-documented as a consequence.

In 2016, the Canadian Partnership Against Cancer (CPAC) – an independent organization funded by the federal government with the mandate of improving cancer control in Canada – conducted a national survey of over 13,000 patients across the country who were 1-3 years post-treatment for cancer about their experience in transitioning from specialized oncology care to the larger health care system. *The Experiences of Cancer Patients in Transition Study* found that among adults over 30 years treated for non-metastatic cancer: 8 in 10 patients were experiencing ongoing physical impacts, of which fatigue and changes to sexual function and fertility were of greatest concern; 7 in 10 patients were coping with emotional concerns, especially worry about cancer recurrence, depression, and changes in sexual intimacy; and 4 in 10 patients were facing practical challenges, most notably returning to work/school and securing life insurance (CPAC, 2018). While the majority of patients had either an oncology specialist (42.4%), primary care

provider (22.4%), or both (31.9%) who were responsible for their follow up care, only around half (50.8-56.1%) of them reported that they found help for their concerns easily or very easily and some (19.5-23.5%) reported that they received no help at all (CPAC, 2018). Barriers to help-seeking among respondents included being uninformed that support services for their concerns were available, embarrassment, and a belief that their concerns were a normal part of life after cancer that could not be helped (CPAC, 2018).

Fitch (2008) suggests that health care providers continually assess the supportive care needs of patients to first identify their needs and then tailor the supportive care plan to the patient by providing education, practical support, and intervention as appropriate. These will vary depending on the disease site, the phase of the illness trajectory, and individual preferences for support (Fitch, 2008). Importantly, while patients may identify a need, they may not necessarily desire support to address it; their readiness and openness for support may vary over time (Fitch & Maamoun, 2016; Fitch & Steele, 2010). That being said, health care providers should make offers of supportive care as part of open and ongoing conversations with patients about their treatment so that they are aware of available resources and given the choice of if and when to access support (Fitch & Maamoun, 2016; Fitch & Steele, 2010). Dialogue about supportive needs is a vital piece of patient care as evidence overwhelmingly supports associations between unmet supportive care needs and high distress, poor psychosocial adjustment and quality of life, and increased utilization of health care services (e.g., emergency room visits) (Carlson & Bultz, 2004; Davies et al., 2018; Edib et al., 2016; Fitch & Steele, 2010; Hodgkinson et al., 2007). It has been argued that psychosocial distress should be considered the “sixth vital sign” of cancer care and regularly screened for along with temperature, blood pressure, heart rate, respiration, and pain; in June 2009 this notion was endorsed by the International Psychosocial Oncology

Society (Bultz & Carlson, 2005; Bultz & Johansen, 2011). Thus, provision of supportive care is of benefit to the individual patient *and* is in the best interest of the health care system in reducing costs and demand on resources. As such, there is an impetus to devote resources to research that develops and evaluates supportive care services, especially brief interventions suitable for busy clinics (Fitch, 2008; Fitch & Maamoun, 2016).

### ***A Provincial ‘Push’ for Sexual Health in Oncology***

Among the various categories of needs within the realm of supportive care, sexual health has recently garnered more attention and prioritization, at least at the policy-level. In 2016, Cancer Care Ontario published *Interventions to Address Sexual Problems in People with Cancer*, a report co-authored by experts in the field that provides guidelines and recommendations for addressing the sexual health concerns of oncology patients (Barbera et al., 2016). The report is intended for use by Ontario oncologists, radiation therapists, urologists, gynaecologists, primary care physicians, surgeons, nurses, physiotherapists, social workers, psychologists, psychiatrists, and counselors; reflecting the multidimensional nature of sexual health and the need for cross-disciplinary action when addressing sexual concerns in cancer. Barbera et al. (2016) organize the report according to the sex of the patient (cis-men and cis-women) and common areas of sexual concern, specifically; sexual response, body image, intimacy and relationships, altered sexual satisfaction and function, vasomotor symptoms, and genital changes. For each condition, the authors recommend intervention approaches and provide a review of the associated literature in support of the practice guideline. Notably, psychosocial counselling is a recommended intervention for all conditions, with the omission of men’s sexual response, men’s genital changes and men’s vasomotor symptoms. Couples-based psychosocial interventions were recommended when partnered, particularly for concerns related to body image, intimacy and



relationships. Other treatment recommendations include physical exercise and pelvic floor physiotherapy; pharmaceutical treatments (e.g., phosphodiesterase type 5 inhibitors); hormone therapies (e.g., estrogen and testosterone replacement) or their alternatives (e.g., paroxetine, venlafaxine, gabapentin); use of vaginal moisturizers, lubricants, and dilators; use of vacuum erectile devices, intracavernosal injections, and medicated ureteral systems for erections; regular genital stimulation in any form (e.g., masturbation, intercourse); and acupuncture. Above all else, the primary recommendation identified by Barbera et al. (2016) as “vital” (p. 8) regardless of patient sex or presenting condition, was:

...that there be a discussion with the patient, initiated by a member of the healthcare team, regarding sexual health and dysfunction resulting from the cancer or its treatment. Ideally, the conversation would include the patient’s partner, if partnered. This issue should be raised at the time of diagnosis and continue to be re-assessed periodically throughout follow-up... The recommendations that follow cannot be used unless someone has taken the initiative to ask. (p. 8)

Thus, the most basic recommendation from Cancer Care Ontario is that healthcare providers take it upon themselves to have ongoing conversations with their patients and their partners about sexual health. Unfortunately, as evidenced by patient needs assessments (see Harrison et al., 2009; Wang et al., 2018) and *The Transition Study* (see CPAC, 2018) individuals diagnosed, treated, and in recovery from cancer do not always receive support for the physical and psychosocial changes to sexual health that they experience as a consequence of their disease and treatment. The release of Cancer Care Ontario’s report appears to signal a shift at the systemic level toward addressing sexual function and intimacy during cancer and into

survivorship and is a call to primary and allied health care professionals working in oncology to regularly address the sexual health concerns of their patients and their partners.

## **Overview of Sexual Health in Oncology**

### ***Sexual Health Concerns of Cancer Patients***

Given the emphasis on the need to communicate about sexual health concerns in oncology care, it is important to review the common and long-lasting sexual concerns that arise during the cancer experience. Cancer treatments, including surgeries, radiation therapy, chemotherapies, and hormonal treatments – though often necessary for survival – impart several adverse effects on the sexual functioning of patients. Sexual concerns in cancer are not limited to cancers found in sexual or sexualized organs, such as prostate, testicular, breast, and gynecological cancers, but are also reported among patients of other disease sites including bladder, CRC, lung, bone, hematologic, and head and neck cancers (Behringer et al., 2013; Bober & Varela, 2012; Falk & Dizon, 2020; Katz & Dizon, 2016; Shell et al., 2008). The prevalence of sexual difficulties fluctuates according to the type of cancer and treatment but, on average, 50-60% of patients experience sexual concerns (Schover, 2019). Most sexual dysfunctions are the result of physical damage to anatomical structures (e.g., pelvic floor, autonomic nerves involved in genital blood flow, sensory nerves activated during arousal) and physiological systems (i.e., endocrine system, reproductive cycles) involved in the sexual response cycle but may also be secondary to the other physical effects of cancer (e.g., fatigue, chronic pain, nausea) (Falk & Dizon, 2020; Schover, 2019).

Male patients report low libido, erectile dysfunction (i.e., inability to gain or maintain an erection), less rigid erections, fewer spontaneous erections, loss of penis length and/or curvature of the penis, ejaculatory dysfunction (e.g., anejaculation), delayed or absent orgasm, less intense

orgasm or decreased sensation, dysorgasmia (i.e., pain during orgasm), climacturia (i.e., leakage of urine at climax), and urinary and bowel incontinence more generally (Katz & Dizon, 2016; Lee et al., 2006; Matthew et al., 2005; Nazareth et al., 2001; Schover, 2019; Wilt, 2008). Androgen deprivation therapy for the treatment of prostate cancer almost inevitably impacts men's sexual functioning, with prevalence rates of erectile dysfunction and low libido among these patients as high as 80% 1-year after beginning treatment (Falk & Dizon, 2020; Katz & Dizon, 2016; Schover, 2019). Similarly, female patients report low interest and desire for sex, vaginal dryness, difficulties with arousal and lubrication, dyspareunia (genital pain associated with intercourse), anatomical changes that affect penetration (e.g., shortened vagina, vaginal fibrosis or total occlusion), decreased pleasure and difficulty with orgasm, changes in genital sensations, and urinary and fecal incontinence (Chang et al., 2019; Falk & Dizon, 2020; Harrington et al., 2010; Schover, 2019; Ye et al., 2014). Cancer and its treatments can also impact fertility (e.g., premature menopause due to disruptions in endocrine systems), which is of particular concern among young female patients (Ahmad et al., 2015; Falk & Dizon, 2020; Schover et al., 2014; Stanton et al., 2018). Research suggests that these functional complaints can last long into survivorship, with studies reporting sexual dysfunction 2 and 5 years into remission (Harrington et al., 2010).

While physical changes may be the primary mechanism underlying sexual dysfunctions in cancer, there are also several psychological challenges to patients' sexual health within oncology (Falk & Dizon, 2020; Schover, 2019). Changes in sexual functioning themselves are associated with relational distress, anxiety, depression, low self-esteem, embarrassment and shame (Çakmak et al., 2010; Persson et al., 2004) as well as decreased desire and frequency of sexual activity (Abbott-Anderson & Kwekkeboom, 2012; Chang et al., 2019; Falk & Dizon,

2020; Harrington et al., 2010; Schover et al., 2014). Moreover, patients face challenges to their body image due to cancer therapies – such as loss of hair, fluctuations in weight or muscle mass, changes to skin (e.g., scarring), alterations to sexualized organs (e.g., loss of breast or testicle), and fecal or urinary incontinence – which are associated with decreased sexual satisfaction, low desire, and avoidance of sexual activity (Falk & Dizon, 2020; Katz & Dizon, 2016; Schover, 2019). The psychological burden of the cancer diagnosis itself can impact patients' sexual functioning, desire, and satisfaction (Falk & Dizon, 2020; Katz, 2005) and remains a quality of life concern among advanced cancer patients (Bond et al., 2019).

Alterations to sexual functioning, fertility, and physical appearance from cancer treatments are also a source of distress to patients' self-concept, including affronts to their perceptions' of their sexual selves and worry about their desirability and acceptance by their partners (Falk & Dizon, 2020; Fergus et al., 2002; Katz & Dizon, 2016; Paterson et al., 2016). Sexual dysfunction is associated with poor communication between patients and their partners, and in turn, marital distress (Badr & Taylor, 2008). Embarrassment or desire to protect one's partner can lead couples to avoid discussing changes to their sexual relationship, while inflexible attitudes about sexual activity and pre-existing relational difficulties can further challenge adjustment (Gilbert et al., 2009; Katz & Dizon, 2016; Schover, 2019; Traa et al., 2015). In other cases, couples negotiate with one another to find new and alternative ways of maintaining intimate connection outside of their usual forms of sexual intimacy and tend to adjust better when they do so (Chang et al., 2019; Gilbert et al., 2009; Katz & Dizon, 2016; Traa et al., 2015). Patients who are not partnered also experience sexual concerns, most notably about dating and engaging in sexual activity with new partners in their altered bodies after cancer (Falk & Dizon, 2020; Kurowecki & Fergus, 2014).

While trends in prevalence rates and descriptions of the physiological and psychological consequences of a cancer provide a broad and population-based understanding of the burden of cancer on sexual health, it is important to underscore the variability of the impact of these changes on the individual patient. The type of concerns and the distress that they generate for each patient, as well as the prioritization of sexual health by the patient over the course of their cancer experience will, in reality, manifest themselves in highly individualized ways. Sexuality is deeply personal, and as such, aspects of an individual's identity, history, and larger cultural and social systems including age, gender, religion, and identification with sexual minority communities will shape how cancer disrupts their sexual well-being (Chang et al., 2019; Gallo-Silver & Weiner, 2006; Hill & Holborn, 2015; Katz & Dizon, 2016; Li & Rew, 2010).

#### ***Disparity in Sexual Health Research and Interventions by Disease Site***

Historically, research conducted in sexual health within oncology has largely focused on breast, prostate, and to some degree gynaecological cancer and testicular cancers (Falk & Dizon, 2020; Maiorino et al., 2016; Miles et al., 2007; Perz et al., 2013) and the majority of couples-based interventional research conducted to date has been performed with patients diagnosed with breast or prostate cancers (Badr & Krebs, 2013; Gilbert et al., 2009; Jonsdottir et al., 2018; Regan et al., 2012). This disparity may exist because of researchers' focus on the sexual impacts of cancers in sexual or sexualized organs, like breasts and genitals, and overlooking the sexual impacts of cancer in other areas of the body (Gilbert et al., 2009). While these cancers are more obviously related to sexual function, one can also imagine how the shock and devastation of a cancer diagnosis, the physical and emotional toll of treatments, changes to autonomy and relational roles within couples (i.e., patient-caregiver), and existential worry about the future hold the potential to impact both sexual health and intimacy (e.g., desire, body image, pain,

relational distress) in all kinds of cancers, not only those in which the tumour is located in a sex organ or erogenous zone. As previously reviewed, there is evidence from relatively limited research with CRC, bladder, lung, head and neck, bone, and hematologic cancer patients to support this idea (Bober & Varela, 2012; Falk & Dizon, 2020; Katz & Dizon, 2016; Shell et al., 2008). Moreover, it stands to reason that in the case of CRC, sexual organs are also frequently affected. The anus and the rectum are considered to be sources of sexual play and pleasure amongst both homosexual (Allensworth-Davies et al., 2008; Dangerfield II et al., 2018) and heterosexual couples (McBride, 2019; McBride & Fortenberry, 2010); a point which appears to be largely ignored, perhaps because of the stigma and taboo associated with anal sex acts (McBride & Fortenberry, 2010).

Given this trend in sexual health research in oncology, it is perhaps unsurprising that in the Cancer Care Ontario report on *Interventions to Address Sexual Problems in People with Cancer*, Barbera et al. (2016) based their recommendations for women principally on studies of women with breast cancer and their recommendations for men predominantly upon research of men with prostate cancer. Regardless, the authors indicated that they believe their recommendations could be generalized to all cancer sites. Their inclusion of a statement on generalizability indicates that the agency recognizes that sexual health concerns in cancer are not limited to those disease sites that researchers have most often studied. Moreover, while it *may* be true that clinicians can apply their recommendations across cancer types, without appropriate research into the specific sexual health needs of the understudied disease sites, it is possible that there are yet unknown variations in sexual health concerns across sites that call for more tailored approaches to care.

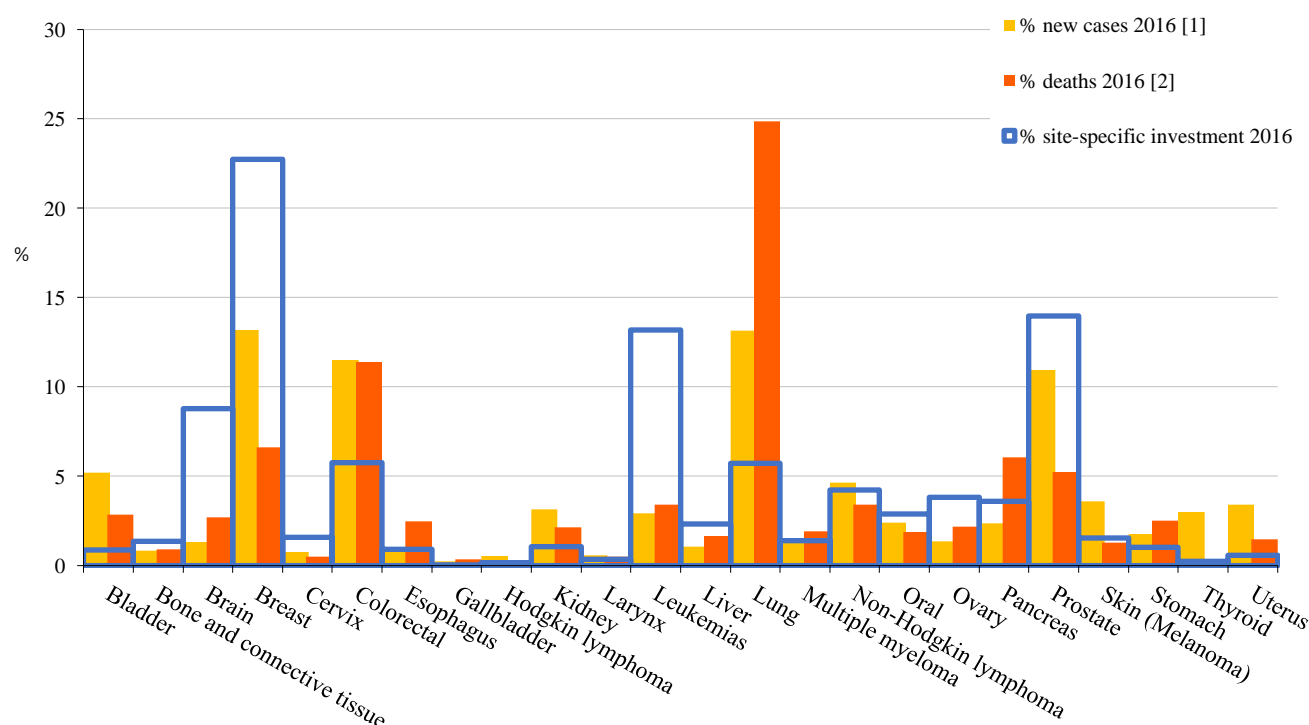
While tumour site likely contributes to disparities in sexual health research in cancer, examining funding allocation to research across disease sites in cancer points to another potential reason for the disparity. The Canadian Cancer Research Alliance (CCRA, 2019a) – an organization of local, provincial and federal agencies and charities dedicated to funding the majority of Canadian cancer research – recently released a report of trends within cancer research investment occurring between 2005-2016. In their report, the CCRA (2019a) indicates that over the 12 years reviewed, “an increasing proportion of research investment was specific to one or more cancer sites” (p. 1). Breast cancer, prostate cancer, and leukemias consistently held the top three positions for number of dollars invested in disease-specific research (CCRA, 2019a) and in 2016 half of the total annual cancer research funds in Canada were devoted to only these three cancers – specifically, breast (25.6%), prostate (12.9%), and leukemias (11.6%) (CCRA 2019b).

When evaluating research investment across disease sites, it is important to consider burden of disease as researchers have argued that disease sites with the greatest burden should receive the highest amounts of funding to drive research that mitigates the societal costs (e.g., financial, human) and stands to impact the most amount of people (Carter & Nguyen, 2012). The CCRA (2019a) did so by examining indices of disease burden of several cancer sites – specifically the number of new cases and the 5-year net survival rate – against the research investments (in dollars) made in each during 2016 and concluded that, “there are cancers that may benefit from targeted funding programs” (p. 6). *Figure 1* is reproduced with permission from the CCRA report (2019a) and illustrates their overall findings. Notably, lung and CRC received considerably less research investment than breast and prostate cancer despite the former cancers having higher death rates than the latter (6.6% for breast and 5.3% for prostate versus

11.4% for colorectal and 24.8% for lung) and comparable projected rates of new cases to the latter (13.8% for breast and 11% for prostate versus 11.5% for colorectal, and 13.1% for lung); the result appears to be a mismatch between disease burden and allocation of research funding. Similar trends in mismatched funding have been documented by others in Canada (see Coronado et al., 2018) and in the United States (see Carter & Nguyen, 2012).

**Figure 1**

*Distribution of 2016 Site-Specific Cancer Research Investment (\$286M) by New Cancer Cases and Cancer Deaths in 2016*



[1] Statistics Canada. Table 13-10-0111-01 - Number and rates of new cases of primary cancer, by cancer type, age group and sex for 2010 (Quebec) and 2016 (Canada (excluant le Québec)). (accessed 2019-02-06)

[2] Statistics Canada. Table 13-10-0142-01 - Deaths, by cause, Chapter II: Neoplasms (C00 to D48) for 2016. (accessed 2019-02-06)

Research on the differences in reported health-quality of life outcomes between breast, prostate, and CRC survivors is another index of disease burden that further underscores the need for increased research in CRC in particular. Research demonstrates that the severity of



impairment in domains of health quality of life vary according to cancer type, with female CRC patients reporting poorer general health than female breast cancer patients and male CRC patients reporting poorer general health and physical health and more activity limitation compared to prostate cancer patients (LeMasters et al., 2013). The authors suggested that treatment related symptoms and outcomes specific to CRC, such as patients' need for a colostomy or ileostomy, may contribute to the worse health-quality of life outcomes in CRC survivorship relative to breast and prostate cancer (LeMasters et al., 2013). Additionally, the authors suggested that increased emotional distress and poor mental health reported by male CRC patients and prostate cancer patients in the early phases of survivorship may be related to sexual dysfunctions experienced as a result of treatment for these cancers and the affront to male patients' masculine identities (Fergus et al., 2002; LeMasters et al., 2013; Oliffe, 2009).

Overall, the disproportionate allocation of research funding and attention by cancer site in combination with the relative disparities in burden of disease paint a bleak picture for investigation into the sexual health needs of CRC. It stands to reason that with more money invested in research of specific cancer sites, such as breast and prostate cancers, endeavours such as studying the sexual health of patients with those diagnoses can be more easily – and more frequently – undertaken. In contrast, cancers like CRC that receive less funding, despite high disease burden and unique challenges to quality of life, are at a significant disadvantage when it comes to conducting research in general, let alone on issues of supportive care such as sexual health.

## **The Complex Care Needs of CRC Patients**

### ***Prevalence and Treatment of CRC in Canada***

CRC refers to the development of malignancies in the cells of the colon and/or rectum; due to their close anatomical location and similar tissue composition, cancers in these two sections of the gastrointestinal (GI) tract are grouped together (CCS, 2019f). The most common type of CRC, adenocarcinoma, begins in the mucus cells of the colon and rectum while rare forms of the disease include small cell carcinoma and squamous cell carcinoma (CCS, 2019f). In Canada, CRC is the third most diagnosed cancer (excluding non-melanoma skin cancers) and represents the second highest mortality rate for cancer among Canadian men and the third highest mortality rate for cancer among Canadian women (CCS, 2019a). It is estimated that 1 in 13 Canadian men and 1 in 16 Canadian women will develop CRC in their lifetime (Canadian Cancer Society, 2019a). In Ontario specifically an estimated 11,595 new cases of CRC were diagnosed in 2018, representing an age-standardized incidence rate of 72.3 cases per 100,000 individuals and the second most diagnosed cancer after female breast cancer (Cancer Care Ontario, 2018). The risk of CRC diagnosis increases significantly with age (Cancer Care Ontario, 2018), but recently there are warnings that the incidence of CRC among younger adults (30-49 years) is on the rise (Cancer Care Ontario, 2017).

Treatment approaches for CRC vary according to the characteristics of the tumour (e.g., location, stage, primary or recurrent) as well as the patient (e.g., general health, individual preferences, history), however, a combination of interventions including surgery, chemotherapy, and radiation are commonly performed (CCS, 2019e). Surgical interventions vary in level of invasiveness and range from local excisions to remove polyps and tumours on the surface lining of the GI tract in precancerous or early stages of the disease, respectively; to bowel resections,

the most common surgeries for CRC, which involve the removal of the lymph nodes and the portions of the intestine where the malignant tumour is located (e.g., colon, rectum, anal canal); to pelvic exenterations performed for advanced stages of the disease or when the cancer has spread to adjacent organs wherein the lymph nodes, rectum, colon, reproductive organs, and bladder may be removed (CCS, 2019e). In cases where surgery is contraindicated, chemotherapy can serve as the primary means of intervention while adjuvant chemotherapy is commonly used following surgery in the treatment of stage 2 and 3 CRC. Radiation is more commonly used in rectal cancer than in colon cancer (CCS, 2019e). In the case of colon cancer, radiation may be used preoperatively to reduce the size of the tumour, during or after surgery to treat any remaining cancer cells that were not surgically removed, in tandem with chemotherapy (i.e., chemoradiation) to treat the cancer non-surgically, for symptom management in advanced stages (e.g., blockage, pain), and to treat metastases in other areas of the body (American Cancer Society, 2019; CCS, 2019e). Within rectal cancer care, it is more common for radiation to be used before surgery to decrease the likelihood of recurrence, during surgery at the site of the tumour to remove any remaining cancerous cells, alone or as part of chemoradiation for symptom management and/or in lieu of surgical interventions, and to treat metastases in other organs (American Cancer Society, 2019; CCS, 2019e).

While these interventions hold the potential to treat CRC, prolong life, and manage symptoms, they can also introduce their own challenges. Arguably the most significant and distinctive treatment-related consequence of CRC is the need for a temporary or permanent ostomy. Following pelvic exenterations and some bowel resections – when all or parts of the small intestine, colon, rectum, and/or anal canal are removed – a colostomy or ileostomy may be performed (CCS, 2019e). These surgeries involve bringing a portion of the intestine through the

abdominal wall to the skin surface to create an artificial opening called a stoma (CCS, 2019b, 2019e). A colostomy refers to the creation of a stoma using the colon while an ileostomy refers to the creation of a stoma using the last part of the small intestine, or ileum (CCS, 2019e). A pouching system, or ostomy appliance, is worn over the stoma and secured to the abdomen to collect stool and gas from the GI tract as it exits the patient's body (CCS, 2019c). Patients do not have control over the stoma and as such cannot control the elimination of waste as one can with a functional anal sphincter (CCS, 2019b). Colostomies and ileostomies may be a temporary consequence of cancer treatment, as in cases where they are later reversed by reattaching the intestine after adequate time is given for healing following the bowel resection, or they may be a permanent consequence of treatment, as in cases where such large portions of the intestinal tract were removed to treat the cancer that too little healthy tissue remains for reattachment (CCS, 2019b, 2019e). In cases where the colostomy or ileostomy is permanent, the rectum and anus may be completely removed and sewn closed, thus precluding any waste from exiting as before, whereas patients with temporary ileostomies and colostomies are left with an anus and may expect some mucous to continue to pass through the orifice (CCS, 2019b).

While ileostomies and colostomies are not required in the treatment of all cases of CRC, for patients who *do* receive them, they can pose significant additional challenges to adjustment during treatment and into survivorship (CCS, 2019d). As such, the necessity of performing permanent colostomy and ileostomy surgeries is used as a measure of quality of care in CRC (CPAC, 2014; Porter et al., 2014), though some warn of the shortcomings in relying on permanent stoma rates as the sole indicator of surgical quality as many factors influence surgical outcomes (CPAC, 2014; Codd et al., 2014; Yoganathan et al., 2015).

In terms of ostomy surgeries performed for CRC specifically, a 2019 report on the *Pan-Canadian Standards in Rectal Cancer Surgery*, co-authored by an expert panel in rectal cancer surgery, mentions that rates of permanent colostomy surgery in Canada have “dramatically” decreased due to advancements in surgical approaches. However, the authors do not support their claim with evidence of changing rates over time, nor do they provide current incidence rates for surgeries (see Rectal Cancer Surgery Expert Panel, 2019, p. 4). In a population based analysis, Porter et al. (2014) report that among the 10,559 patients who underwent bowel resections for primary rectal adenocarcinoma in nine Canadian provinces over the course of the fiscal years 2007/2008 – 2011/2012: 3,895 (36.9%) patients underwent permanent stoma (i.e., ileostomy or colostomy) surgery, 3,501 (33.2%) patients underwent temporary stoma surgery, and 3,163 (30%) patients did not receive a stoma as part of their treatment (Porter et al., 2014). They report significant variation in rates of permanent stoma surgeries across provinces, with a range of 35.1% - 51.4% ( $p < 0.0001$ ). Porter et al. (2014) suggest that geography may account for the variation observed as they found significant relationships between patients’ place of residence and permanent ostomy rates such that patients living in rural areas, and especially remote areas, had significantly higher rates of permanent stomas than those living in urban areas ( $p = 0.0003$ ); patients with longer travel times to their hospital had significantly higher rates of permanent stomas than those with short commutes ( $p < 0.0001$ ); patients living in low income areas had higher permanent stoma rates compared to those living in high income areas ( $p = 0.003$ ); and patients living in areas with lower immigrant density had higher permanent stoma rates than those living in areas with high immigrant density ( $p < 0.0001$ ).

The Canadian Partnership Against Cancer (CPAC, 2014) reported similar trends, however, they found no relationship between neighbourhood income and rates of permanent

colostomies and, interestingly, when they examined provincial rates individually, they found that Ontario's pattern differed from national trends. In Ontario specifically, the CPAC (2014) found an unusual pattern in which patients living 90 minutes or more from the nearest surgical hospital had lower rates of colostomies (30.5%) compared to those living 40 minutes or under from the hospital (34.9%); this anomaly within their findings had no obvious explanation and the authors reported that it requires further investigation. Some have suggested systemic differences in care and decision-making may underlie the national geographic variations in permanent colostomy rates between urban and rural/remote patient residence, for example surgeons may opt for colostomies to reduce the likelihood of hospital re-admissions associated with bowel dysfunction when patients live far from the hospital (CPAC, 2014; Forte et al., 2014). In provincial population-based analyses, rates of permanent colostomies for rectal cancer have been reported to be as high as 53% in Manitoba (Latosinsky & Turner, 2009), 47% in northern Alberta (Pelletier et al., 2013), and 48% in Nova Scotia (Richardson et al., 2013b). Cancer Care Ontario (2004) estimated its province's rate to be much lower, at 15%, but importantly did not provide any data to support the estimate. In addition to geography, research supports relationships between being male, low-lying tumours, and advanced staging with receiving a permanent colostomy as part of rectal cancer treatment (Richardson et al., 2013b) whereas being treated in a high-volume hospital and by a surgeon with specialized knowledge in CRC are associated with lower likelihood of permanent colostomy (CPAC, 2014; Ricciardi et al., 2011; Richardson et al., 2013a)

Such discrepancies in permanent ostomy rates notwithstanding, what is most concerning are cases in which permanent ostomies are performed unnecessarily. Alarming, medical chart reviews of the 224 patients in Nova Scotia, identified via their provincial cancer registry, who

received permanent colostomies as part of their treatment for primary rectal adenocarcinoma between July, 2002 - June, 2006 revealed that as many as 65 (29%) may have received them inappropriately (Richardson et al., 2013b). The authors defined colostomies as “potentially inappropriate” in cases where medical charts showed that the tumour had not encroached on the anal-sphincter, where the tumour was located 6 cm or more from the anal skin, or where there was no documented reason for performing the permanent colostomy (Richardson et al., 2013b, p. 705). In these cases, multivariate analyses suggested that being male and being treated in low- or medium-volume hospitals were associated with receiving a colostomy unnecessarily (Richardson et al., 2013b). Overall, the available data on rates of ostomy surgeries indicate that a significant majority of patients treated for CRC in Canada are faced with the task of adjusting to life with an ostomy, temporarily, if not permanently.

### ***Unique Adjustment Challenges of CRC Patients With Ostomies***

LeMasters and colleagues (2013) suggest that the poor health-quality of life outcomes reported by CRC patients relative to breast and prostate cancer patients may be a function of the unique symptoms and adjustment concerns that present themselves in the disease process and treatment of CRC. Compared to population norms, survivors of CRC report worse physical quality of life, long-lasting symptoms related to bowel function, distress related to cancer, and higher levels of depression (Jansen et al., 2010). Most notably, CRC patients living with stomas due to their disease report poorer health-quality of life compared to CRC patients without (Mols et al., 2014; Näsval et al., 2017). Those living with colostomies and ileostomies experience significant disruptions to several areas of their lives as they work to accommodate this substantial change to their body and one of its most basic – and private – functions.

Overall, patients who receive an ostomy as part of treatment for CRC report lower health quality of life than those not requiring the procedure (Mols et al., 2014; Näsvalld et al., 2017). Research suggests that patients who receive a temporary ostomy appear to experience more difficulty in adjusting to this change than those who receive a permanent ostomy, with these patients reporting decreased quality of life and reduced life satisfaction over time (Smith et al., 2009). Smith et al. (2009) hypothesize that patients with permanent ostomies are forced to reconcile that they must live with the ostomy for the remainder of their lives, whereas, the hope of ostomy reversal interferes with adaptation in cases where the ostomy is expected to be temporary (Smith et al., 2009). Patients with temporary stomas may be more inclined to view their current situation as poor because they expect their circumstances to improve with reversal and their hope of reversal may equally lead them to avoid the mentally effortful and emotionally painful process of acknowledging the change and adapting to the stoma (Smith et al., 2009). Even after reversal, however, patients can continue to experience disruptions to their bowel functioning (e.g., frequency and urgency to defecate, fecal incontinence) that can negatively impact their physical, psychological, and social well-being for several months, and sometimes permanently (Taylor & Morgan, 2011). Perhaps more devastating, in some cases what is planned as a temporary stoma preoperatively can end up being permanent due to a number of medical reasons (Kim et al., 2016).

Getting one's bearings on how to care for the stoma and pouching system is a central focus of adjustment (Danielsen et al., 2013; Sun et al., 2013). From a practical standpoint, a patient with a colostomy or ileostomy must get used to a new way of having bowel movements and establish new hygienic practices in response. Often through trial and error, patients figure out which of the available ostomy pouching system products they prefer; ease of use, the



positioning and functioning of their stoma, and the quality and cost of the product may all contribute to individual preferences for products (Sun et al., 2013). As part of this process, patients must also learn how frequently they need to empty or change their appliance and how to care for the cleanliness of the stoma and surrounding skin (Sun et al., 2013). Establishing such routines takes time, effort and practice, and unfortunately despite best-laid plans patients can still experience leakage, failure of an ostomy appliance, and blockages (Sun et al., 2013). Moreover, patients are often forced to change their lifestyle in order to care for the ostomy. For example, patients may have to empty and clean their bag multiple times a day, alter their diet (e.g., avoid certain foods, alter size and timing of meals, skip meals) to help manage stoma output, and spend time caring for the skin around the stoma that can become irritated from cleaning or from the pouching system adhesive (Lynch et al., 2008; Sun et al., 2013). Ostomy irrigation – passing water through the stoma to empty the bowels – can provide a sense of security to patients by reducing daily output, but also requires regular planning and increased time in the restroom (Carlsson et al., 2010; Sun et al., 2013). The presence of a stoma is also associated with increased fatigue and decreased appetite, perhaps due to the stress of caring for and monitoring the ostomy to avoid embarrassing mishaps (Näsvall et al., 2017; Sun et al., 2013). Patients with ostomies also risk developing bothersome or painful hernias at the site of the stoma where the abdominal wall has been weakened (Näsvall et al., 2017) or phantom rectum pain at the site of their excision (Fingren et al., 2013), both of which are associated with poor health-quality of life.

Travelling or being away from home, even for short periods of time, can pose additional obstacles and effort. Simply using a seatbelt properly can be difficult depending on the location of the stoma, while carrying out bathroom routines in public restrooms can be a practical and emotional challenge for patients, especially when privacy is compromised (Lynch et al., 2008;

Persson & Hellström, 2002; Sun et al., 2013). Additionally, to ensure they are never without supplies, patients must plan ahead either by carrying additional supplies with them or by contacting ostomy product suppliers in their destination before their departure (Lynch et al., 2008; Sun et al., 2013). Lastly, some patients with ostomies report difficulty returning to work with the appliance, due to demands of physical labour and/or fear of leakage, as well as financial strain from purchasing ostomy supplies, the full cost of which may not be covered by government reimbursement programs or private insurance (Chongpison et al., 2016; Maydick, 2014; Persson & Hellström, 2002; Smith et al., 2017)

It is easy to imagine how the changes to long-standing bathroom routines and the very nature of the change at hand – a basic and private bodily function – may make the adjustment process to an ostomy feel like a daunting task. Unsurprisingly, in addition to the practical challenges of caring for the ostomy, patients also face significant psychological and emotional distress related to living with an ostomy. Symptoms of depression are more prevalent among patients with ostomies following CRC than those without and can persist long into survivorship (Chongpison et al., 2016; Krouse et al., 2009). The loss of control over bowel functioning can be a destabilizing and distressing experience for patients. Without control over the stoma output, patients commonly experience worry and embarrassment about odour, noise, and leakage from the ostomy appliance, which can lead them to withdraw socially (Danielsen et al., 2013; Lynch et al., 2008) and to limit their physical movements and activities (Persson & Hellström, 2002; Sun et al., 2013). Impairments in social well-being are well documented among CRC patients with ostomies and are significantly worse than in those without (Jansen et al., 2010; Mols et al., 2014). Patients must navigate disclosure of the ostomy; deciding when, how, and who to tell about the ostomy can be more difficult than discussing the cancer diagnosis itself and is

sometimes not easily avoided when others notice the ostomy themselves (Danielsen et al., 2013). Patients express concerns about how others will react, fearing most especially judgment and stigma by others, including family and friends (Persson & Hellström, 2002; Smith et al., 2017). In an effort to conceal the ostomy bag, patients describe wearing loose clothing (Danielsen et al., 2013; Persson & Hellström, 2002); in some cases, they feel forced to find entirely new wardrobes that cover the stoma and do not interfere with its functioning (Sun et al., 2013). Importantly, the physical and lifestyle changes imposed by the colostomy can have devastating consequences on the patient's body image and self-identity, for example they may perceive the ostomy as incongruent with their sense of self (e.g., ostomies are for people in old age), as impeding their ability to express their self-identity (e.g., expressions of femininity or sexuality), or as having irreparably altered their sense of self post-operatively (e.g., feeling disfigured, 'incomplete,' or of lesser value as a person) (Danielsen et al., 2013; Manderson, 2005; Näsvalld et al., 2017; Persson & Hellström, 2002; Smith et al., 2017).

Related to these general psychosocial and identity-based concerns, Bulkley et al. (2013) demonstrated that the presence of an ostomy can impact patients' spiritual well-being, comprising both their existential well-being (e.g., inner peace, meaning of life) and religious well-being (e.g., connection to higher power). Five years following CRC diagnosis, many patients reported ambivalent spiritual well-being in relation to the ostomy (e.g., the ostomy is the cost of survival), while others reported negative impacts on spiritual well-being (e.g., loss of prior physical and sexual functioning, feeling let down by their doctors) (Bulkley et al., 2013). That being said, some individuals are able to integrate the ostomy into their sense of self and think about their ostomies in positive terms, for example being grateful that the ostomy has given them the opportunity to engage in life again after cancer (Bulkley et al., 2013; Smith et al., 2017).

While patients' spirituality can be helpful in their adjustment to an ostomy (Bulkley et al., 2013; Li et al., 2012), the ostomy itself can be disruptive to engagement in religious or spiritual practices of the individual (e.g., fasting). This is most notable among some worshipers of Islam who perceive ablution – a cleansing of oneself and environment that must be performed before engaging in the *salat*, an act of worship performed multiple times per day – as invalidated by the involuntary passing of gas or feces (Akgül & Karadağ, 2016; Iqbal et al., 2016). Beliefs regarding uncleanness are associated with less participation in community worship and increased performance of ablution (Akgül & Karadağ, 2016; Iqbal et al., 2016).

Importantly, the disruptions imposed by the ostomy may also extend to patients' partners, when they are in a relationship. Partners report spending more time at home, being less engaged in recreational activities, and taking on a role in ostomy care (Çakmak et al., 2010; Persson et al., 2004). Stability in their relationship with their partner and in receiving family support are associated with patients' higher quality of life (Leyk et al., 2014; Nichols & Riemer, 2008). Thus, partners' acceptance of the ostomy is important. While partners can experience reactions of discomfort or disgust toward the colostomy (Çakmak et al., 2010; Persson et al., 2004) and fear of causing harm to the patient's stoma (Li, 2009), others react more favourably (e.g., "It doesn't bother me" p.13) (Northouse et al., 1999). Partners may demonstrate support for patients in their adjustment to colostomies after CRC both instrumentally (e.g., direct or indirect care of ostomy) and emotionally (e.g., empathy, acceptance or reassurance) (Altschuler et al., 2009; Northouse et al., 1999). CRC treatments, primarily radiation and surgical interventions, can result in sexual dysfunctions (e.g., pain, vaginal dryness, erectile dysfunction) (Li, 2009; Vural et al., 2016) that can vary depending on type of surgery and tumour location (Traa et al., 2012). Patients who receive ostomies report significantly worse sexual function and body image

concerns than those without (Cotrim & Pereira, 2008; Sun et al., 2016; Traa et al., 2012). These patients have the additional challenges of managing odour, noise and leakage during sexual activity which requires additional preparation, reduces spontaneity, and can interfere with patients' ability to relax and be present during sex (Averyt & Nishimoto, 2014; Manderson, 2005; Ramirez et al., 2010; Vural et al., 2016). The ostomy can also impose restrictions/limitations in sexual positions (Vural et al., 2016) and altered body image and lowered self-esteem can lead patients to disruptions in patients' sexual identities and interest in sex (Li, 2009; Li & Rew, 2010; Vural et al., 2016). In turn, couples can experience significant decreases in their level of sexual activity (Çakmak et al., 2010) and difficulty communicating about these sexual changes (Ohlsson-Nevo et al., 2012; Traa et al., 2014).

### ***The Unmet Supportive Care Needs of CRC Cancer Patients***

The Registered Nurses' Association of Ontario (RNAO, 2019) recommends that all patients who anticipate living with an ostomy receive access to care by a nurse with specialized training in wound, ostomy, and continence care. They also recommend that institutions develop ostomy programs that provide pre- and post-operative education and support by interdisciplinary teams, as well as the integration of assessments of psychological distress (i.e., anxiety and depression) and self-identity (i.e., body image and sexuality) to inform individualized care plans (RNAO, 2019). Similarly, in their *Pan-Canadian Standards for Rectal Cancer Surgery*, the Rectal Cancer Surgery Expert Panel (2019) recommends access to interdisciplinary teams, including enterostomal nurses for patients with a planned stoma surgery to counselling, education, and ostomy care. It is vital that patients receive accurate preoperative information about living with an ostomy so that their expectations about the challenges they may face in adjustment are realistic and perceived as a normal occurrence during this process (Danielsen et

al., 2013). Research suggests that patients living with ostomies following CRC make more frequent visits to their specialist oncology doctors and are more likely to access allied health care (e.g., psychology, social work) than patients without ostomies (Mols et al., 2014)

Unfortunately, research on the unmet needs of CRC patients indicates that, despite the documented challenges faced by this particular population, their needs often go unaddressed. Retrospective case note reviews of nurses treating patients following hospital discharge for CRC surgery in Australia revealed that 42% of patients had unmet supportive care needs, and over 50% of these unmet care needs related to physical functioning (e.g., wound and stoma care, bowel function, pain) (Harrison et al., 2011). Interestingly, one of the most frequently made notes by nurses indicated provision of ongoing re-assurance and support to patients, namely normalizing the symptoms they were experiencing post-discharge (Harrison et al., 2011). This study also showed that expressions of unmet support needs amongst patients were highest within a week after discharge, followed by a period of decline and then rise again at six months, likely related to some change in treatment or disease (e.g., stoma reversal, advancement of disease, completion of adjuvant therapies) (Harrison et al., 2011). Self-report assessments of patients undergoing chemotherapy for CRC in Japan also revealed several areas of unmet needs, however, this study suggested the greatest needs were in psychological domains (e.g., fear of cancer spreading, concerns about worries of loved ones, worry about treatment) and that unmet needs were associated with anxiety and depression (Sakamoto et al., 2017). Focus groups conducted with Canadians treated for CRC similarly uncovered unmet needs across the disease trajectory. Patients expressed inadequate information from their healthcare team, particularly related to the side effects/risks of drugs (e.g., peripheral neuropathy), the financial burden of treatments, and the gynaecological impacts of treatments among female patients (Ho et al., 2016). Patients also

expressed a feeling of abandonment in the transition period to survivorship and a perception that healthcare providers did not empathize with the devastation and lifestyle changes imposed by living with a colostomy (Ho et al., 2016).

Together, these results suggest that CRC patients need ongoing physical and psychosocial support care during treatment and post-discharge. Notably, a self-report survey of American gastrointestinal cancer survivors indicated that a majority of patients (59%) experienced inadequate social support from professionals, family, friends, and community organizations, despite high reports of depression (59%), fear (66%), and anxiety (67%), and of concern, only a minority of patients (40%) felt empowered in their care to advocate for themselves (Raymond, 2018). These results suggest that patients have difficulty reaching out for support themselves despite high distress, highlighting the need for proactive supportive care in CRC. This is particularly imperative when considering the high unmet care needs of cancer patients overall (CPAC, 2018; Harrison et al., 2009; Wang et al., 2018), and the relatively poorer health of CRC patients among them (LeMasters et al., 2013).

### **Summary of Research Objectives**

Given the high, yet relatively unaddressed needs of this oncology population, I endeavoured to fill this breach in cancer care through three sequential qualitative studies. As a collection, these intend to begin to address the unmet supportive care needs of CRC patients and their intimate partners, and their sexual health needs in particular.

Study 1 entails a qualitative grounded theory analysis of couple reports of their experiences of sexual engagement following surgery for a permanent colostomy to treat CRC. This study addresses the research question of: What are couples' lived experiences and concerns in their sexual adjustment to one partner's permanent ostomy after CRC?

Study 2 entails an embedded-case study analysis of a novel online intervention designed to facilitate conversations with these couples about the sexual changes. The analysis uses post-treatment interviews with two couples who completed the intervention and my observations as their facilitator as the sources of data. This study addresses the research question of/question(s): What are couples' responses to and perceptions of an online couples-based intervention for sexual adjustment to an ostomy after CRC?

Study 3 entails a thematic analysis of transcripts of interviews with healthcare providers about their perceptions of the barriers to engaging patients with CRC and their partners in the trial of the intervention from Study 2. This study addresses the research question of/question(s): What are the systemic, patient-, healthcare provider-, and intervention-related barriers to recruiting patients living with ostomies after CRC and their partners in research on a couples-based sexual health intervention?



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## **Chapter 2**

### **Study 1, Grounded Theory Analysis of Couples' Sexual Adjustment to Permanent Colostomies after Rectal Cancer**

For patients with colorectal cancer (CRC), the third most commonly diagnosed cancer in Canada (Canadian Cancer Society, 2019), sexual dysfunction is a prevalent and distressing side-effect of treatment (Averyt & Nishimoto, 2014; Donovan et al., 2010; Hendren et al., 2005; Sun et al., 2016). A systematic review found that 5%-88% of men and about 50% of women experience some form of sexual dysfunction following surgery for CRC (Traa et al., 2012a). The type and degree of sexual dysfunction experienced by patients can vary depending on the location of the tumour, surgical approach, and adjuvant therapies used to treat the disease, with significantly poorer sexual functioning reported among rectal patients and those who receive radiation therapy and abdominoperineal resections (APRs), a procedure which involves the removal of the rectum and the creation of a stoma (Averyt & Nishimoto, 2014; Donovan et al., 2010; Milbury et al., 2013; Schmidt et al., 2005; Traa et al., 2012a). Surveys of patients 5+ years after treatment suggests that these sexual problems can persist long into survivorship and are worse among those with ostomies (Sun et al., 2016).

#### **Sexual Concerns of Patients with Colorectal Cancer and Colostomies**

Common complaints among male CRC patients following treatment are erectile dysfunction and problems with ejaculation (e.g., pain during ejaculation, retrograde ejaculation, loss of ejaculation) (Donovan et al., 2010; Dowswell et al., 2011; Hendren et al., 2005; Traa et al., 2012a). Female CRC patients report dyspareunia (i.e., pain during sex), lack of lubrication, shortened vagina, vaginal stenosis (i.e., narrowing and/or loss of flexibility of vagina), and changes to orgasm (e.g., decreased intensity; difficulty or inability to achieve orgasm) (Averyt & Nishimoto, 2014; Canty et al., 2019; Donovan et al., 2010; Traa et al., 2012a). All patients can

also experience decreases in the frequency of sexual activity, less desire and interest in sexual activity, nerve damage resulting in decreased sensation in sexual organs, concerns about body image (e.g., weight gain, scarring, hair loss, stoma), as well as fatigue and changes to fecal and urinary continence that interfere with sexual engagement (Averyt & Nishimoto, 2014; Donovan et al., 2010; Traa et al., 2012a).

Patients who receive an ostomy (i.e., ileostomy, colostomy) as part of their treatment for CRC report significantly more disruptions to sexual functioning, sexual satisfaction, and body image than patients who do not require an ostomy (Cotrim & Pereira, 2008; Reese et al., 2014; Sun et al., 2016; Traa et al., 2012a), and those requiring permanent colostomies experience significantly more sexual problems than those with temporary colostomies (Ozturk et al., 2015). Patients with colostomies commonly report significant disturbances to their body image that affect their desire to engage in sex, including fears of leakage, gas, odour, and noise from their stoma during sexual activity (Junkin & Beitz, 2005; Manderson, 2005; Vural et al., 2016). In turn, they are recommended to engage in additional personal hygiene routines prior to engaging in sexual activity (e.g., change pouch, irrigate) and often opt to wear specialized clothing to cover and secure their stoma pouch during sexual activity; unfortunately these provisions also impede the spontaneity of sexual interactions (Averyt & Nishimoto, 2014; Ramirez et al., 2010; Vural et al., 2016). The ostomy may also impact the positions patients are able to engage in during sex, and as a result, the ways in which they would naturally relate to their partner during a sexual encounter (Vural et al., 2016). Manderson (2005) highlights how the patients' loss of control in their bowel continence when living with the stoma, and their resultant vigilance of their bowel functioning during sexual activity, belies their ability to engage in "idealized" sex that is characterized by a freedom to lose control (p. 409).

The aforementioned disruptions to sexual functioning and body image can result in significant emotional distress to patients, including depressed mood and challenges to patients' perceptions of their sexual self-identity (Dowswell et al., 2011; Hendren et al., 2005; Junkin & Beitz, 2005; Sun et al., 2016; Vural et al., 2016). Importantly, the experiences of sexual dysfunction in CRC are multifaceted, with factors such as age, social support, global quality of life, and pre-morbid sexual functioning, impacting the experience of sexual disturbance and distress following CRC (Donovan et al., 2010; Milbury et al., 2013; Traa et al., 2012b). Unfortunately research has largely focused on the biological aspects of sexual function and dysfunction in CRC (Milbury et al., 2013; Traa et al., 2014), and few studies have included the partners of patients to understand how CRC and the patient's colostomy impact both the partner and the couples' sexual relationship (Traa et al., 2012a).

### **Impact of CRC and Colostomies on Couples' Sexual Relationship**

The limited research conducted with partners of CRC suggests that the impact of sexual changes on CRC patients extends to their partners. A comparative analysis of self-reported sexual functioning and satisfaction among partners and age- and sex-matched controls found that partners of patients living with colostomies after rectal cancer reported lower sexual satisfaction, poorer sexual function, and greater decreases in frequency of sexual activity (Silva et al., 2014). Partners of CRC patients have also reported significantly more emotional distress and less social support than their ill-partners (Northouse et al., 2000). Despite their distress, they describe setting aside their own sexual needs by not raising these concerns with the patient or their health care team, in lieu of prioritizing the medical needs of the patient (Traa et al., 2014). Some partners also view the sexual problems experienced by the patient as personal to them, and as such leave the decision to the patient to seek out medical assistance for sex-related concerns at

their own pace, if at all (Ohlsson-Nevo et al., 2012). Taken together, these studies suggest that partners are also impacted sexually by the cancer, but their communication of their distress can be stalled out of concern for the other.

In relation to the ostomy, interviews conducted with individuals living with ostomies due to a diversity of health conditions (e.g., cancer, Crohn's disease) suggests that *both* patient and partner must negotiate notions of disgust and embarrassment about excretion in the context of sexual interactions (Emslie et al., 2009; Manderson, 2005; Ramirez et al., 2010). Individual interviews and focus groups with spouses have confirmed that feelings of discomfort and disgust on their behalf impact their desire to engage intimately with patients (Çakmak et al., 2010; Persson et al., 2004), while others have reported largely positive reactions to the stoma by partners (Northouse et al., 1999). Patients primarily cope with their feelings by using a new bag, covering and securing the pouch during intercourse, hiding the stoma from their partner, and humour – if not ceasing sexual activity all together (Manderson, 2005; Ramirez et al., 2010). Patients often fear rejection by partners, and in some cases these fears are realized in partners expressing negative reactions to the stoma, withdrawing, or leaving the relationship (Altschuler et al., 2009; Junkin & Beitz, 2005; Sun et al., 2016). According to accounts relayed by patients, partner-caregivers can begin to view them as child-like in their dependency; an image of the patient that is incompatible with them as a sexual being and in turn impacts the partner's desire to engage in sexual activity (Manderson, 2005). In the patients' experience, partners who were accepting and supportive of their changed bodies and who were able to simultaneously maintain roles as "caregiver" and "lover" to the patient if they were involved in their ostomy care helped to affirm their sexual desirability (Emslie et al., 2009; Manderson, 2005; Ramirez et al., 2010). Emslie and colleagues (2009) suggest evidence of gender differences in sexual adjustment

around the ostomy. Specifically, while both men and women with ostomies expressed disgust over their stoma, at least initially, they described the women in their sample as able to overcome these feelings and re-engage in sex while many of the men in the sample described long-term, ongoing struggles to accommodate the stoma into their self-image and sexual relationship (Emslie et al., 2009).

In focus groups of CRC patients and their partners conducted separately, both members of the dyad indicated that their sexual relationship was not of primary importance during the treatment phase of the illness and for many participants maintaining other forms of affection (e.g., hugging, kissing) and a strong relationship were of utmost importance post-treatment, more so than the ability to have intercourse (Traa et al., 2014). Relatedly, Ohlsson-Nevo et al. (2012) found that following treatment for CRC, some couples were able to resume sexual activities in some form, others replaced sex with alternative expressions of intimacy, and still others ceased sexual activity all together. When the sexual relationship was nonexistent post-surgery, patients expressed marked distress over this loss in contrast to partners who were described as apathic toward this change (Ohlsson-Nevo et al., 2012). These findings suggest that the priority and importance placed on sexual intercourse can vary over the course of treatment and recovery, as well as between partners in the dyad.

### **Study Objective**

Cancer diagnosis and treatment impacts *both* patients and their partners/spouses and, can in turn, disrupt the sexual relationship of couples. The current analysis was part of a larger qualitative investigation into couples' overall adjustment to living with an ostomy following CRC treatment. The aim of this study is to add to the limited body of literature about the sexual and intimate concerns experienced by patients and their partners during and after treatment for



CRC. By taking a qualitative approach to inquiry, this study aims to provide an experiential account of couples' sexual and intimate adjustment to a permanent colostomy. Such descriptions of couples' sexual and intimate experiences may provide clinically useful information, including insights into the supportive care needs of these couples and the ways in which they try to cope in their sexual adjustment.

## **Method**

### **Procedures**

#### ***Participant Recruitment***

This study was reviewed and approved by the Sunnybrook Health Sciences Centre Research Ethics Board (#071-2013) and the York University Human Participants Review Sub-Committee (#2013-114). Participants were recruited from the Odette Cancer Centre (OCC) at Sunnybrook Health Sciences Centre in collaboration with an Ostomy Advanced Practice Nurse, who contacted former and current patients who appeared to meet the recruitment criteria with an invitation to participate. Invitations were made in a non-coercive manner; patients were informed that participation was voluntary and would have no repercussions on their current or future healthcare at the OCC. Interested patients were referred to the first author and study coordinator (Molly McCarthy), who contacted them by telephone to provide them with details of participation and confirm eligibility of the patient and their partner/spouse. Interviews of eligible couples who agreed to participate were scheduled at a time most convenient for the couple, with the choice of meeting either in a private room at the hospital or in their home. The study coordinator completed the informed consent process with the couples in person before beginning the interview and study procedures.

Recruitment was limited to patients who had received an APR and permanent colostomy during treatment for rectal cancer. In order to capture dyadic adjustment experiences to the

colostomy, recruitment was limited to couples who were in a partnership that began prior to cancer diagnosis and couples were recruited a minimum of 3-months following the patient's last active treatment (e.g., surgery, adjuvant chemotherapy and/or radiation). Eligible dyads were between the ages of 18-80 and could speak and read English. Participation was open to couples of all sexual orientations and couples did not have to be married. Recruitment was discontinued when data met saturation for the larger study on couples' general adjustment to the colostomy following rectal cancer, meaning no new information about overall adjustment was emerging from subsequent interviews. While attempts were made to balance the sample by patient gender and to recruit participants with diverse ethnic, cultural, religious and sexual identities of various ages and life stages, the final sample of 11 couples consisted primarily of heterosexual couples and male patients and their partners/spouses.

Of the 24 prospective patient participants who expressed a willingness to be contacted by the study coordinator, only 11 couples agreed to participate following their conversation. Five of the couples declined once contacted due to privacy ( $n = 2$ ), time constraints ( $n = 1$ ), health of partner ( $n = 1$ ), and undisclosed reasons ( $n = 1$ ). The remaining eight prospective participants failed to respond to multiple attempts at an initial contact by the study coordinator ( $n = 5$ ), failed to respond to follow up contact by the study coordinator after an initial conversation about the study purpose ( $n = 2$ ), or failed to respond at attempts to schedule an interview after completing eligibility screening with the study coordinator ( $n = 1$ ). Of the 13 couples who declined or failed to respond to the study coordinator, nine consisted of female patients and their partners.

### ***Dyadic Interview***

Semi-structured, in-person interviews were conducted in the hospital or participant's home with both members of the dyad present to allow patients and partners the opportunity to

share and respond to one another's perspectives about their adjustment experience. As part of a larger study about the overall adjustment patterns of couples to a permanent colostomy following rectal cancer, the interview consisted of open-ended questions to elicit information about couples' adjustment experiences to the cancer and colostomy. The interview was semi-structured to allow researchers the flexibility to explore avenues of interest as they arose through discussion. The first and second interviews were conducted by the author and study coordinator (Molly McCarthy) and her research supervisor (Dr. Karen Fergus) together, while subsequent interviews were conducted by the author and study coordinator alone. Neither interviewers had prior relationships with the participants. At the time of the interviews, Molly McCarthy was a Master's student in Clinical Psychology and Karen Fergus worked as a clinical psychologist and associate professor with over 15 years of clinical and research experience in psycho-oncology. One interview was conducted per couple and lasted approximately 1.5 hours; all interviews were audio-recorded.

### *Analysis*

The inductive, constant comparative method of grounded theory was chosen to guide the analysis (Glaser, 1978; Glaser & Strauss, 1967) as it provided a systematic method for generating an overarching theory or explanatory account of couples' sexual and intimate adjustment to a permanent colostomy after rectal cancer, that is grounded in the experiences of such couples. The audio recordings of interviews were transcribed verbatim and N-Vivo for Mac Version 12 software was used to organize and manage the text during analysis. The interviews were read in their entirety for understanding and appreciation of couples' overall adjustment experience. Following this reading, sections of text pertaining to couples' sexual and intimate adjustment were selected for analysis; this included references to sexual function, the couple's

sexual relationship, and the patient's body image when made in relation to sexual identity and/or expression. These portions of text were taken from sections of the transcript when couples were asked direct questions about their sexual relationship as well as in instances when couples themselves made reference to aspects of their sexual and intimate relationship at other points during the interview. Those selected portions of text were then divided into 'meaning units'; a block of text (e.g., a few words or several sentences) that convey a single concept or idea (Giorgi, 1970). In an inductive approach to analysis, each meaning unit was labeled through the process of 'embodied categorization' in which the authors empathetically engaged with the text in an effort to capture the meaning contained in the unit of analysis (Rennie & Fergus, 2006). The result is the creation of a category of abstracted meaning that is tied to or grounded in the text. Using open categorization, existing categories were revised based on meanings contained in subsequent units of analysis. In cases where the meaning was not yet captured, existing categories were revised and/or expanded, or an entirely new category label and definition was created. The list of categories was considered "saturated" when no new categories of meaning emerged from further analysis of the text; in this analysis this occurred with the tenth couple, who happened to be the only gay couple within the sample. Constant comparison of categories encouraged the assessment of theoretical and conceptual relationships between them to create higher-level categories of abstracted meaning and ultimately a 'core category' capturing the phenomenon overall. Throughout the analysis, memos pertaining to the authors' assumptions and biases, conceptual ideas and observations, and theoretical linkages between categories were recorded to facilitate this process. Ultimately, consensus on category synthesis and organization was achieved through input and collaborative discussions among the study coordinator (Molly

McCarthy), her research supervisor (Dr. Karen Fergus), and team members in the Psychosocial Oncology Laboratory.

### **Researcher Reflexivity**

In the current analysis, in terms of epistemological reflexivity, a stratified critical realist ontology with an interpretivist epistemology was assumed (see Weed, 2009). It was assumed that couples experienced real changes in their sexual adjustment to the ostomy that would be shared but responded to and made meaning of in different ways by each couple and/or individual within the dyad. It was also assumed that the phenomena under study – in this case, the sexual changes and the ways in which couples coped with them – could not be measured directly and therefore, some degree of interpretation was necessary during data analysis.

In keeping with this interpretivist epistemology, it is important to acknowledge subjective reflexivity and theoretical reflexivity within the current analysis (Willig, 2012) – specifically the primary analyst's personal experiences and theoretical assumptions given exposure to the literature. The primary analyst had conducted extensive reviews of existing literature in the area of the psychosocial adaptation of couples following CRC and an ostomy; thus she had some prior knowledge of such couples' experiences, at least to the extent that they were reported in the existing literature from either the perspective of the patient or partner individually. Moreover, the primary analyst conducted all of the dyadic interviews and thus was familiar with the set of interview transcripts as a whole prior to undertaking the more fine-grained grounded theory analysis. As such the analyst had a theoretical sensitivity toward the area, but in keeping with the inductive nature of the analysis held no pre-conceived notions about what may emerge from the analysis (Weed, 2009).

Lastly, with regard to subjective reflexivity, the primary analyst has personal connections to cancer. One of the primary analyst's mother was previously diagnosed and treated for breast cancer and, during the course of the current investigation, was diagnosed and treated for thyroid cancer. As a witness to the coping of her parents with cancer diagnosis and treatment, the primary analyst also brings an empathy, grounded in her own personal-experience, to the interpretative meaning-making that occurs between the researcher and the research data in a grounded theory analysis (see Rennie & Fergus, 2006).

## **Participants**

### ***Demographics***

The participants consisted of eleven patients and their partners ( $N = 22$ ) who attended Sunnybrook Health Sciences Centre in the Greater Toronto Area for rectal cancer treatment. Patients were 57.72 years old on average (range: 42 – 80 years) and consisted of eight men and three women. Patients were diagnosed with rectal cancer, either primary ( $n = 8$ ) or recurrent ( $n = 3$ ), and were an average of 31 months post-diagnosis ( $SD = 18.26$ , range: 7 – 59) and 23.55 months post-colostomy surgery ( $SD = 17.13$ , range: 4 – 54) at the time of the interview. All patients had undergone abdominoperineal resection (APR) and a permanent colostomy surgery, with two patients receiving loop colostomies. Additional surgeries included a coccygectomy ( $n = 1$ ), a resection of lateral seminal vesicle ( $n = 1$ ), a lateral colon resection ( $n = 1$ ), and a posterior vaginectomy ( $n = 1$ ). Patients also receive neoadjuvant radiation and chemotherapy ( $n = 11$ ) and adjuvant chemotherapy ( $n = 8$ ).

Ten of the patients were in heterosexual relationships and one of the male patients was in a same-sex relationship. The average length of relationship was 26.45 years (range: 4 – 55 years). Six of the couples shared children and one male patient had children from a previous

relationship; the majority of children were of adult age. Partners had a mean age of 55 years (range: 37 – 76 years). The majority of participants were Caucasian, had at least some post-secondary education, and were employed or retired; please refer to Table 1 for details on the ethnicity, employment status, education, and relationship satisfaction of patients and their partners. Three couples completed their interview at the hospital, while the remaining couples opted to have the interview in their home.

**Table 1**

<i>Ethnicity, Educational, and Employment Demographics</i>		
	Patients (n)	Partners (n)
Ethnicity		
White/Caucasian	9	9
Asian	0	1
East Indian	1	1
Hispanic	1	0
Highest Level of Education		
Elementary	1	0
High school	1	2
Some college/university	3	3
College degree	2	2
Undergraduate degree	3	2
Master's degree	0	1
Doctoral degree	1	1
Employment Status		
Full-time	4	6
Part-time	0	0
Self-employed	0	1
Retired	5	4
Disability support/leave	2	0
Relationship Satisfaction*		
Distressed	0	0
Non-Distressed	11	11

\*As measured by the Kansas Marital Satisfaction Survey and a cut off-score of 17 (Crane et al., 2000)

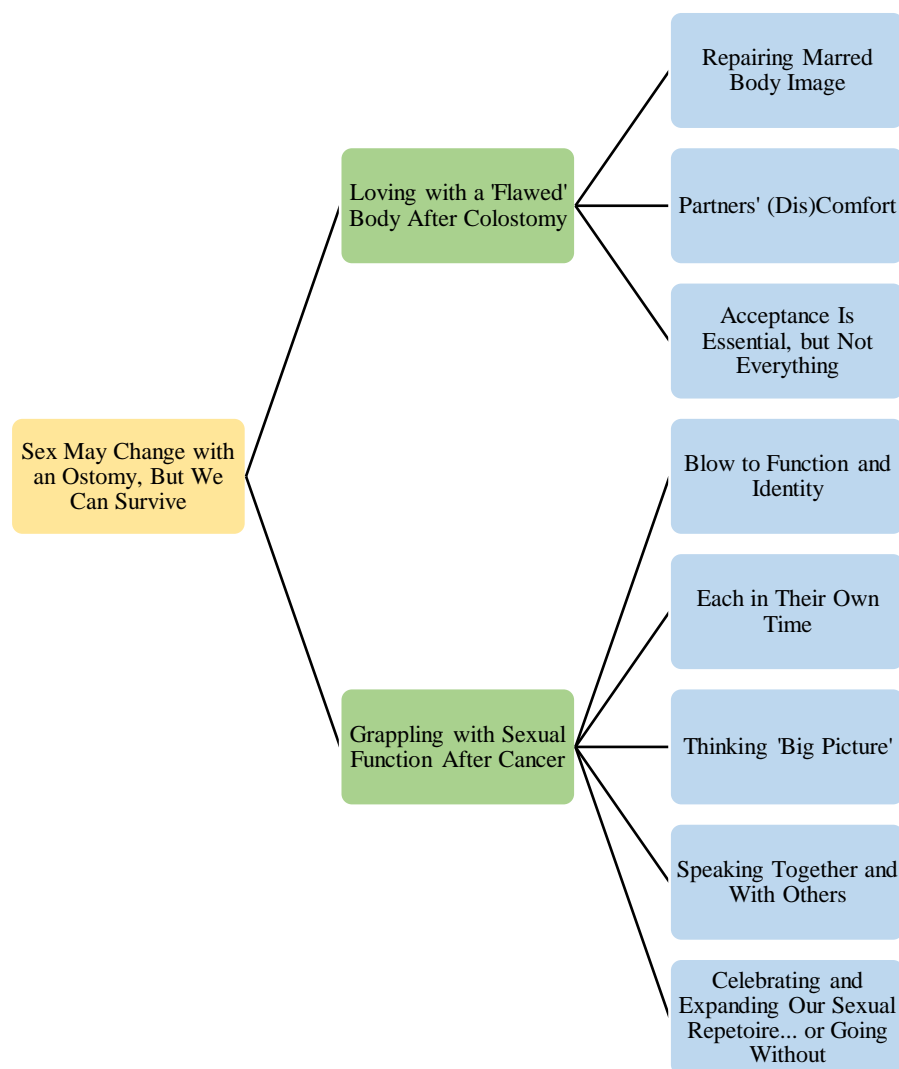
## Results

The grounded theory analysis yielded a hierarchical model for couples' sexual adjustment to a permanent colostomy after rectal cancer (Figure 2). Initially 48 lower-order categories, which were closely tied to the content and meaning of the 11 interview transcripts, were coded. Lower-order categories that were consistently coded together and/or that represented dimensions of the same concept or experience were subsumed into one category, leaving a total of 40 lower-order categories. These 40 lower-order categories were then grouped by themes and became the defining properties of eight third-order categories; see Appendix A for list of third-order categories, their defining lower-order categories and their endorsement by couples. The third-order categories were then grouped into two second-order categories: (a) *Loving With a 'Flawed' Body After Colostomy* and (b) *Grappling with Sexual Function After Cancer*. These second-order categories reflect the two primary concerns expressed by the couples and distinguish between the couples' coping with the impact of the stoma on the patient's body image and repercussions of the cancer treatments on sexual function. A core category of *Sex May Change with an Ostomy, but We Can Survive*, represents the top of the hierarchy and captures the meaning of all categories below it.



**Figure 2**

*Theoretical Model of Couples' Sexual Adjustment to a Permanent Colostomy After Rectal Cancer with Core-, Second-, and Third-Order Categories*



*Sex May Change With an Ostomy, but We Can Survive* captures the notion that couples – while acknowledging and grappling with the profound impacts of both the cancer treatments and ostomy on the sexual functioning and body image of the patient – have the capacity to remain connected as a dyad. The use of *we* in the core category refers to the couple, as its own entity, that is able to sustain itself and be resilient in the face of sexual changes brought on by the cancer

and ostomy; the couple is separate from or *more than* their bodies and the ways in which they relate sexually to one another. *Survive* as opposed to a more transformative verb such as *thrive* or *grow* was deliberately chosen for the category. Survival implies continued existence and function, but a need to actively work to maintain this state in the face of some kind of threat. Though some couples described instances when the cancer and ostomy had brought them closer together in their intimacy as a couple, hinting at a kind of growth or evolution, these same couples continued to be challenged as they worked through new and longstanding physical and psychosocial concerns in their sexual adjustment. With the backdrop of cancer as the context for the ostomy and consequent sexual changes, *survive* also speaks to the attitude that couples may take in relation to adapting to the sexual changes – that they are a nominal ‘cost’ for the survival of the patient and, in turn, the couple.

The following results are organized by second-order categories: (a) *Loving With a ‘Flawed’ Body After Colostomy* and (b) *Grappling with Sexual Function After Cancer* and present the eight, third-order categories that describe the challenges faced by couples in their adjustment and their ways of coping. Defining properties of the third-order categories appear in italics, with direct quotes from partners and patients as illustration of some of these.

### **Loving With a Flawed Body After Colostomy**

One of the primary overarching concerns encountered by couples in their sexual adjustment was the psychological impact of the ostomy on the patient’s body image. As sex entails relating physically to one’s partner and being physically ‘exposed’ in front of one’s partner, the patient’s comfort and confidence within their body and the acceptance of their body by their partner is intertwined with their openness, willingness, and ease in being sexually intimate with their partner.

### ***Repairing a Marred Body Image***

Patients expressed dislike for the appearance of the stoma and the pouching system, viewing these changes as an imperfection or an abnormality. One male patient who took particular pride in his physicality remarked, “Well to me it’s like my body was perfect before, like it was. Now it’s this thing... I think it’s ugly” (Male patient, Couple 5). Another male patient perceived himself as defective relative to others, explaining “It’s interesting... We all have completely seamless exteriors in terms of our skin and our bodies and I don’t, right? And I see that as a break, or a defect, or a fault in sort of [me]” (Male patient, Couple 2), while another’s sense of self had fundamentally changed with his physical appearance, as he described it “...the whole notion of disfigurement... that’s what you have to psychologically get over. Every time you take off your clothes... every time you go to the washroom, it’s there. And you know you’re not the same person you were before” (Male patient, Couple 9). For these patients, the ostomy represented *a fault in me*. The ostomy was also regarded as the source of *unparalleled self-consciousness* within the relationship, manifested in the patient’s heightened sense of awareness when being physically intimate with their partner, a feeling summarized by one patient as follows:

I find it [referring to the colostomy] confining both physically and psychologically... I don’t even know a parallel to draw to other things that I would have been self-conscious of prior to this. I don’t know of anything else in my life previously that would have been the same way... I don’t think it necessarily has negatively impacted our sex life but at the same time, every once in a while, there’s those heightened moments of awareness where I’m – I feel a little “Ughh” about it, right? Like it’s just, like “Ugh dammit”. (Male partner, Couple 2).

For some patients, their sense of discomfort with the ostomy also lead to them *covering my embarrassment* by physically hiding the stoma from their partner. One female patient recalled

her efforts to conceal the stoma from her young son and husband, at least in the beginning of her adjustment:

... even at bedtime, right, just being covered and not anyone seeing my bag or my pouch or anything, right. No one – like they knew what was there – but nobody had seen it. It was very important to me in the beginning. And now I don't, like or I'd be dressing or undressing and you [referring to her husband] would look at me and I'd apologize all the time. "Oh I'm sorry... Sorry I have an ostomy. Sorry, you know, this sorry that about it." And now I get dressed and it's there and I don't apologize for myself constantly cause otherwise I'd be apologizing for the rest of my life. (Female patient, Couple 11)

Other patients, even years after their colostomy surgery, had never uncovered the stoma in front of their partner – "I'm kinda embarrassed I don't want to show her [referring to his partner]"

(Male partner, Couple 5). To ease their discomfort around the stoma, several patients described purchasing and wearing more discrete appliances or some kind of clothing, such as underwear or lingerie designed for the ostomy or a type of band around their midsection that covered the stoma and pouching system, thereby *turning "the ugliest thing" into something "quite attractive"*.

Patients made references to the unsightly appearance of the ostomy products (e.g., "ugly", "gross", "a big band-aid", "not sexy") and wearing smaller appliances or pieces of clothing over their ostomy pouch supported their ability to engage in sex with their partner by making them feel "sexier". Ostomy attire sometimes offered a functional benefit as well in helping to secure the pouch and thereby reducing worry of leakage. One patient explained her process of making the colostomy "pretty":

I got home from the hospital, of course, they send you with the ugliest thing [referring to ostomy pouch] home with you...so I got on the internet right away and I found this website called Ostomy Secrets... it's [like] Victoria Secrets... but this is for girls who are living with Colitis... and they quickly showed underwear, I ordered the underwear right away. They also showed a "vixen belt" that you could wear for when you're having sex... So it was the prettiest little lace [belt] that I ordered right away. You know with visions that we, you know, you know... And it's really pretty, in fact most women should order them because it's quite attractive" (Female patient, Couple 1)

Additionally, couples also described *irrigation as a saving grace* in its ability to provide patients with a sense of control over their bowel function and in turn the opportunity to wear smaller, more discrete pouching systems during sexual activity, such as a stoma cap. The impact of irrigation on the patients' sexual well-being was not lost on one partner who commented,

I think the irrigation to me has been a real godsend for you cause you... I think the not being in control part was really off-putting for you... But not to say that you're in complete control now, but it's given you enough control... And I think, just to relate that to the sexual thing now, I think you're a lot less worried that [the ostomy] is going to activate during [sex], yeah... And like I say the odd fart, I love it! (Male partner, Couple 11).

This category suggests that as patients struggle in accepting their changed body from the colostomy, it is important for them to be able to regain some degree of control over their bowel functioning and enhance the attractiveness of the pouching system in order to integrate the stoma into their sense of self.

### ***Partner's (Dis)Comfort***

Partners, for their part, had varying reactions to the stoma. Some described a *private worry*; a fear or discomfort about the ostomy, at least initially, driven by their unfamiliarity with the appliance that was not necessarily shared with the patient. As one female partner recalled her apprehension before her ill-partner's surgery,

I think before the operation I'm really worried. You know it was like, oh my God, he's going to have that thing and... at first I didn't even know what it is... but then we looked the [pamphlets] and... my God I was like the [shallow] part to think that he's going have that thing hanging on him and poo will come out from it (Female patient, Couple 5)

In two cases, partners experienced *uneasiness around the stoma* following surgery but this feeling was not necessarily detrimental to the relationship or the ability of the couple to stay connected. Partners in these cases were up front about their uneasiness. For example, the same female partner expressed that she would rather not see her ill-partner's stoma and he also

preferred not to show her. The other partner who was similarly uncomfortable around the stoma remarked, “I’ll be honest, [laughs] it weirds me out to roll over and put my arm around him and grab a handful of ostomy. Right, I don’t want to do that, just because it’s weird, it’s weird, right.” (Male partner, Couple 10). Notably, his ill-husband did not react negatively or even respond to this comment in the moment but later alluded to “moments of strangeness” as they learn about and adjust to the colostomy, suggesting a level of forgiveness and understanding on behalf of the patient that there may be moments of unease around the stoma during their adjustment. That being said, several partners including both of the partners who endorsed *uneasiness around the stoma*, also expressed that *the ostomy doesn’t matter* when it comes to their feelings of love toward the patient or their desire to engage in sex with the patient. Partners expressed that they were not conscious or aware of the ostomy during intimate moments – “it’s just there, it doesn’t matter... it doesn’t hurt the moment” (Female partner, Couple 2) – and that the ostomy, unlike the cancer surgery and treatments, had not impeded the sexual relationship or forced them to modify their sexual activities – “what I’m looking at is the impact of surgery. Not the fact that he has an ostomy... because I don’t see him with an ostomy” (Female partner, Couple 9).

### ***Acceptance Is Essential, but Not Everything***

Partners, whether or not they explicitly expressed during the interview that the *ostomy doesn’t matter*, described two important ways that they actively demonstrated their acceptance of the patient’s body following the colostomy surgery. One important way that the partners expressed their acceptance was through assurances to the patient that *their beauty is intact*, for example one partner recalled telling his wife, “I’ve said things to [patient] like as long as you’re alive I don’t care if you have a stoma coming out of your forehead” (Male partner, Couple 1) while another partner similarly expressed,

I love [patient] to bits and pieces. This is just a side effect of something that has drastically changed our lives. That's it. The ostomy itself, like I said, I don't care. It doesn't make him look any less attractive to me. You know, he's the same person that I married 6 years ago (Male partner, Couple 10).

A second way that partners demonstrated acceptance of the patient's changed body due to the stoma was to indicate to the patient that there is *no need to cover yourself*, both in moments of intimacy and in daily life at home as they went about their regular activities, when exiting the shower for example. One partner illustrated this acceptance when he told his wife that she could forgo wearing her "vixen belt" during sex:

Male partner: ...it [referring to vixen belt] was cute and I appreciated, you know, the thought but I'd be like, "Okay where's the ostomy belt?" "I dunno?" "Where?" [laughs]

Female patient: And then we decided that, that didn't bug you that much

Male partner: I didn't care, I didn't care, I'm not like that... That's got nothing to do with it, you know, whatever. (Couple 1)

Partners, in turn, expressed that their partner's acceptance of their body with the stoma *makes all the difference* in the health of their relationship, as one female patient expressed:

I could easily see some guy going "This is not what I signed up for. This is disgusting. Like I can't have sex with you anymore". Or whatever, right. So no, like you [referring to her partner] have been – I say to everyone – he's been so amazing about it. Like not once has he said anything remotely demeaning or insulting about it. He's always just been supportive. So I feel super lucky. (Female patient, Couple 11).

Interestingly while discussing their appreciation for their partners' acceptance, some patients imagined that they would have had a much more difficult time dating and entering a new relationship with the stoma, and so were thankful for having a partner who accepted them with the changes to their body. At the same time there was also a feeling among patients that *no matter their partners' support*, they would experience feelings of embarrassment or self-consciousness surrounding their physical appearance and bodily functioning. In other words, partners' acceptance does not negate or preclude patients' negative feelings; patients have inner

worlds and relationships outside of the dyad in which feelings of discomfort can continue to exist regardless of partners' support. In describing his self-consciousness one patient put it as, "...It doesn't matter, if it bothers her [referring to his wife] or not, I'm still self-conscious...I just am. And it's not because it's you but because I am self-conscious about it and protective everywhere else in my life." (Male patient, Couple 2). In turn, this patient's partner uniquely expressed *feeling shut out* by his self-consciousness and covering of his stoma around her, "what bothers me is that he's self-conscious around me and I wish he wasn't... we've been married for 16 years and I've had two children and he's witnessed that. I mean, that's about as intimate as you can be" (Female patient, Couple 2).

### **Grappling with Sexual Function After Cancer**

The other primary concern of patients and their partners was that of the actual or potential impact of cancer treatments on the patient's sexual function. Couples adapted in a number of ways and to various degrees to these changes.

#### ***Blow to Function and Identity***

Less than half of couples reported that their doctors and/or ostomy nurses had warned them of the *threat to sexual function* from the cancer treatments. Patients sustained a number of *intimate anatomical changes* due to their cancer treatments, namely surgical interventions and radiation. These included pain after ejaculation, erectile dysfunction, dyspareunia, vaginal dryness, urinary incontinence, and nerve damage that resulted in genital numbness, lowered sensitivity and chronic pain. In a kind of exploratory period following surgery, patients alone or with their partner, came to discover the impacts of their treatment on their sexual function. Patients also described *painful effects of treatment* that did not necessarily affect their sexual function per se but their ability to be touched or close to their partner, such as when cuddling in



bed. Pain and changes to sexual function interfered with both patients' and partners' ability to remain present during sex and in turn impacted their frequency of sexual activity. Relatedly, some patients reported less interest and desire to engage in sex following their treatments; one female patient described the extent of her *lowered libido* when she recalled perceiving sex almost two years after her surgery as a "wifely duty" (Female patient, Couple 11).

A profound consequence of changes to libido and sexual function on the patient was a shift in their self-identity as a sexual being. Several patients identified themselves, or were identified by their partners, as being highly sexual or valuing of sex prior to their treatments such that their sexuality was a significant part of their sense of self. *But I always liked sex...* captures the notion that for these patients, a change in sexual functioning and/or drive was perceived as an especially profound or unfair loss, thrust upon them. For example, a male patient who had highly identified with his virility as a man described his experience upon learning of his erectile dysfunction as follows: "it [loss of erection] gnawed at me for a while because up until that point in my life, it [sex] was very important to me" (Male patient, Couple 5), while a female patient who could no longer have penetrative sex due to dyspareunia following her surgery lamented, "All this happened to me, and I was the girl who liked sex too" (Female patient, Couple 1).

Notably, the fact that some partners/spouses identified the sexual-self as important to their ill-partners' identity, suggests their keen awareness of the psychological impact of physical change as well as a deep understanding of the other as a person. In particular, an interesting dynamic arose for the gay couple that was interviewed in relation to the patients' change in libido and inability to achieve an erection; his partner expressed a need to *avoid flaunting his function* by hiding when he masturbated – "like when I was 14 years old" (Male Partner, Couple 10) – and not being revealing of his erection in front of the patient. The partner explained that

since the patient was “very sexual” prior to surgery, he felt both guilty for his own functionality and that he had to take these precautions to protect the patient from feelings of inadequacy:

For me it goes back to that moment of “I can do this; you can’t”. And I know, I guess, I don’t want to make this sound superficial, but I know how important that [having an erection] was, or is for you... I guess I don’t want to make you feel like you’re not sexy. (Male Partner, Couple 10).

The patient expressed his appreciation for his partner’s concern and reassured the partner that he would not be bothered by his partner’s masturbation and in fact had even offered to join in on the activity in the past, explaining, “I’m perfectly willing to ‘help out’, but he said himself that he needs to have both people fully involved. It’s not that I’m not involved mentally, ‘cause I am involved mentally; I just can’t be involved physically right now” (Male Patient, Couple 10).

### ***Each in Their Own Time***

Couples varied in their pacing of re-engaging in sexual activity and their prioritization of sex in their overall adjustment. Some couples described a *post-treatment hiatus* from sex to allow time for the patient’s body to heal from the surgery and adjuvant treatments, followed by a *slow re-integration* into sexual activities with particular attention to pain. For example, following his wife’s vaginectomy, one male partner explained his fear of causing her pain, “you really go slowly and check on balance you know the first time, the second time... you don’t feel comfortable going the way it used to be... you are more cautious.” (Male partner, Couple 7). Another couple remained in a period of hiatus – “we’re like roommates” (Female partner, Couple 5) – while the patient sought out medical solutions to his erectile dysfunction. Only one couple described *getting to work right away*, in the sense that the patient was envisioning engaging in sexual activity and was problem-solving and planning around challenges to sexual activity immediately upon returning home from surgery (e.g., seeking out information online, talking to others, buying ostomy lingerie); sex had always been important for this couple. Three

couples described being *in no rush* to tackle any changes to the patient's sexual functioning and had engaged in very limited to no sexual activity at all. One of these couples – the eldest couple in the sample – had ceased sexual activity prior to the patient's cancer as it was not a priority within their relationship, stating “this is a subject that we couldn't care less about” (Male patient, Couple 4). The two other couples indicated that sexual changes were relatively less important to other areas of adjustment, especially the ostomy: “I'd explore those things [referring to sexual aids]...but it hasn't been number one priority” (Male patient, Couple 9).

### ***Thinking ‘Big Picture’***

Couples seemed to naturally take a ‘big picture’ perspective while adjusting to the changes in sexual function experienced by the patient. For several couples, sex was an important part of their relationship prior to the cancer, and so they worked at *keeping ‘it’ a priority*, by being aware of time lapsing between sexual encounters, making time for sex, and for some patients, continuing to have sex despite some pain so that their partner did not go without. This being said, these same couples and others described the notion that as a couple, *we are more than sex*, explaining that their relationship and reasons for loving and connecting with each other encompasses more than the physical act of sex, as one patient described, “even in the beginning we were close for different reasons” (Male Patient, Couple 5). As such, some expressed their willingness to sacrifice sex as part of the relationship to keep the patient alive; for example one male partner talked about the place of sex in his relationship with his ill-wife as follows:

[It is an] important thing in the relationship, right? But if you said to me no more sex... it's sex or life, you know, it's not even a discussion point... it's a very simple answer, right? ... You understand, eh? She's with me [referring to patient]. You know whatever, she's with me. (Male Partner, Couple 7)

Couples also took a bird's eye view of their sexual relationship when they referenced *other factors at play* that were contributing to the changes, other than the impact of the patient's

treatments on his or her sexual functioning. The most common reason cited was age related changes to sexual function and libido, referenced often in such a way that conveyed couples believed to some degree that the changes were *bound to happen* either then or in the not too distant future due to aging, regardless of the cancer experience. Other reasons included children living at home, lack of time, work and family responsibilities, and fatigue unrelated to treatment. Relatedly, three couples described *pre-existing sexual concerns* that appeared to have helped them to take the perspectives of *we're more than sex* and *other factors at play*. For example, as one couple discussed the “sacrificing” that the well-partner was making in having less frequent sex with her ill-husband because of the pain he experienced during ejaculation, she said:

I've been sacrificing, [but like] my tubes are blocked, so I could not have children since I got married to him. He could have married someone else, I even told him that he can if he wants to, and he told me to never say that again – you are my wife, if God is willing to give us children, he will give us [children]. And if it's not meant to be, it's not meant to be. As I say the true relationship is unconditional, so having sex doesn't mean that you love and not having sex doesn't mean that you don't love. (Female partner, Couple 3)

The majority of couples also exhibited *hopeful yet realistic thinking* about their ability to improve and find solutions to the patients' sexual functioning. When discussing the changes, they would encourage one another with hopeful words like “we'll work around it” (Male partner, Couple 1) and “we'll figure it out” (Male patient, Couple 10) but also held realistic expectations about the state of their sex life – “We've accommodated each other, I mean we love each other so you know if you love each other that's life” (Female partner, Couple 6) – and the possibility of improving the patient's sexual functioning, “they [referring to medications for erectile dysfunction] may make a difference, may not” (Male patient, Couple 9).

### ***Talking Together and With Others***

Patients and partners spoke about *open communication* during their adjustment to cancer and the ostomy, such that nothing was off limits, including the partners' changes in sexual

function. One partner emphasized the importance of speaking freely within their relationship, warning that keeping aspects of adjustment hidden from one's partner will "deteriorate your relationship" (Male partner, Couple 7). Another partner joked in conversation about the degree of transparency within the relationship especially since living with an ostomy, and as she did so, implied that there was nothing left unsaid between them:

Female partner: Yeah, yeah, he talks, he talks about it all the time everything – nothing – he doesn't hide anything.

Male patient: I don't hide anything...

Female partner: He doesn't *have* anything [left] to hide anymore [begins laughing]

(Couple 5)

In fact, *finding humour* was a strategy used by the majority of couples in conversing about the changes to their sexual relationship, in order to bring levity and some ease to otherwise emotionally heavy conversations; "humour is something that keeps us going", reflected the same female partner (Couple 5). This approach sometimes included dark humour, as for example, one patient described beginning to resemble "a Ken doll with no bum and a non-functioning penis" (Male patient, Couple 10). One patient however felt quite differently, explaining that joking about his cancer and ostomy was off-limits as "everybody makes jokes about farts and nudity and all these sorts of things but this is sort of that, taken to a very different level" (Male patient, Couple 2) and expressed appreciation that his wife had, perhaps intuitively, known not to joke about this sensitive topic.

Although couples described practicing *open communication* within the relationship, an unexpected process took place during the interview for some of these same couples, and others, during which they exhibited *learning through telling their story*. While partners and patients

discussed their sexual relationship and the changes to the partner's sexual functioning with the interviewer, they sometimes discovered new information about one another. For example, in two cases, female partners' learned for the first time of their ill-husband's willingness to try or actual attempts at using erection-enhancing medications and/or devices. In the case of the gay couple in the sample, it also became clear that the conversation allowed for deeper emotional understanding of the other's experience when the patient noted " ...I didn't realize the guilt aspect. I didn't know about that" and his partner replied, "...look at that [directed to interviewer] – You're learning and teaching us at the same time [laughs]" (Couple 10).

That being said, couples demonstrated *varying willingness and readiness* to discuss their sexual relationship within the context of the interview. Two couples were keen on discussing changes to sexual function or raised the subject themselves – "we do have some stuff we want to talk about with that [referring to sex] too" (Female patient, Couple 1) – while one couple declined to speak directly about the sexual relationship, without providing a specific reason. The remaining couples were agreeable and forthcoming to varying degrees in speaking about their sexual adjustment when the topic was broached about mid-way through their conversation, often checking in with each other first about each of their comfort levels' before proceeding. Their openness suggested they had experiences and thoughts about sexual adjustment to share when provided with a venue for discussion.

Prior to the interview, couples described both positive and negative experiences in speaking with their physicians about the patient's sexual function. On the one hand, couples described experiences in which their *doctors were ignorant or unresponsive* to concerns of sexual functioning. Examples of this included being warned by physicians of possible sexual dysfunction moments before surgery or not at all; feeling distressed during a painful pap smear

after vaginal stenosis and then being misdiagnosed with human papilloma virus; and seeking medical help for pain experienced during ejaculation and receiving a prescription for Viagra in response. Several couples described a lack of information from their health care providers with regard to the underlying medical reasons for the changes to sexual functioning the patient was experiencing or whether these changes were temporary or permanent, leaving them unable to make sense of the changes. As one male partner explained, he and his ill-wife were grappling to understand what had contributed to her inability to have penetrative sex:

But, we've um, to be honest, nobody has actually sat down with a diagram and said definitively: "This is what has happened"... It's, it's pretty grey... It's kinda like, okay so um, insertion is *kinda* working...what's going on? So then you talk to [Dr. 1] and he kinda goes, "Well maybe blah, blah, blah" and then you talk to somebody else, "Well blah, blah", and then you talk to your GP. Like nobody's said well "*This* is why"... Like, I don't know, I'm not a doctor. (Male partner, Couple 1)

Fortunately, couples also expressed *appreciation for medical understanding* when their physician or ostomy nurse fully and appropriately warned them about the possibility of changes to their sexual functioning, took concerted efforts during surgery to try to protect the maintenance of the patient's sexual function, provided them with information or supportive aids (e.g., lubricants), and in one case, discussed the need to accommodate the changes to sexual functioning:

My GP, finally just said "You're gonna have to satisfy yourself in different ways"... I was very appreciative of her... In fact, I was shocked... She's our GP and she's like 73 or something... And she was like right away, she goes..."Well you're working around this aren't you? Cause, you know, it's very important that you guys stay intimate." She was great!... So now we've sort of accepted that. (Female patient, Couple 1)

Couples also described *consulting and comparing with their peers* about sex. Speaking to friends who had not faced the sexual impacts of cancer was helpful in gauging whether aspects of their sexual relationship were similar to or different from their peers as well as for learning how their friends had coped with changes to sexual function that were common among their age bracket

(e.g., vaginal dryness in menopause) apart from cancer treatment. On the other hand, speaking with other patients who had been diagnosed with cancer or living with an ostomy, or their spouses, was helpful in learning about process of sexual adjustment to these specific challenges. Despite these benefits, reaching out for help can be quite challenging; one patient recalled her hesitancy and vulnerability in contacting a patient-peer, “I had the number of someone for ages and I actually felt, I didn’t call her because I was gonna be that depressing person on the phone... there’s a certain shame in like calling being that woe is me person.” (Female patient, Couple 11).

### ***Celebrating and Expanding Our Sexual Repertoire... or Going Without***

In their adjustment to the functional changes experienced by the patients, couples celebrated their sexual relationship. Two couples planned *one “last hurrah!”*, a special date night and time to be sexually intimate, prior to the patient’s surgery. Others were *grateful for some maintenance*, celebrating the sexual functioning that the patient *was* able to maintain after the surgery; as one partner reflected upon her ill-husband’s continued ability to have erections, though not as strongly as before, “it could be nothing – like some men after the surgery are totally impotent so you know it could be worse, so you think of the positive side, right?” (Female partner, Couple 6). Couples also took steps to expand their sexual repertoire in order to accommodate the changes in sexual functioning. In some cases couples integrated and re-integrated *new and old forms of sexual activity* into their repertoire, by emphasizing foreplay, mutual masturbation, and oral sex, as opposed to focusing on penetrative sex as they formerly had. One couple explained their solution to the patient’s pain during penetrative sex as follows:

It’s [referring to penetration] not gonna work. And then it took all the fun out of it – cause I would be anticipating... I’d be like, oh you know, “Oh here we go, we’ve got to do it now”... So now we, uh, just, uh – we’ve almost come back to the way we were



before we were married [laughs]... we just rub. [rubs hands together] (Female patient, Couple 1)

The majority of couples also described their experiences, or at least willingness in the future, to *seek out assistive devices* to support their ability to engage in penetrative sexual activities; for women this included the use of vaginal dilators, vibrators, and lubricants, while for men this included medications for erectile dysfunction only. This being said, two male patients also expressed a belief that there was *no way to modify* their sexual relationship to accommodate the physical sexual changes they were experiencing – pain during ejaculation and erectile dysfunction, respectively. Interestingly, both of these patients remarked – in jest – that the only solution to their problem was for their partner to seek sex outside of the relationship; neither partner found this particularly humorous. These same patients spoke of *seeking out assistive devices*, particularly medications, either without success or as a future plan, but they did not endorse *new and old forms of sexual activity*, suggesting that they had not considered alternative forms of sexual activity and were focused on continuing to have sex in the same ways that they had prior to surgery. As a result, these couples described going without sex more often than not. This belief that there was *no way to modify* was so distressing to one of the patients that he described himself as “ruining” his wife’s life:

She is sacrificing, let’s face it. If you are a human being you have feelings. It is something natural... there is pain and agony [referring to his pain after ejaculation], so what are you going to do? It’s like I’m ruining a life... I feel it in my heart of course, I feel it. She’s sacrificing a lot. I don’t think any other woman would have done it... (Male patient, Couple 3)

Importantly, in the face of the changes to sexual dysfunction, couples also made direct references or allusions to the notion that *intimacy is more than sex*, illustrating that there are non-sexual activities that maintain and sustain their intimate connection as a couple. Partners still described themselves as “affectionate” (Female partner, Couple 9) even though they were not having sex or

expressed appreciation for “just [being] clinch[ed] together and feel[ing] warm side by side” (Male partner, Couple 7). In some cases, couples indicated that the cancer and/or colostomy had enhanced their sense of connection in this way, as the wife of the patient who felt he was “ruining” her life with less sex explained:

I actually think it has brought us closer together... Yeah we have been always together. Even not with words, we don't have to say it, we just sit down, hold hands and you just feel like, okay we are together, no matter what it takes you, you will go through it together. (Female partner, Couple 3)

### **Discussion**

The results from this analysis yielded a comprehensive overview of couples' sexual adjustment to a permanent colostomy after rectal cancer – one that reflected the ability of couples, as a dyad, to survive changes in their sexual relationship. Couples were faced with changes to the patient's sexual functioning in the wake of treatments for CRC, as well as alterations to the patient's body image while living with a stoma. Consistent with previous research demonstrating couples' varied re-engagement in sexual activity following CRC (Ohlsson-Nevo et al., 2012), of the 11 couples that participated: one couple, the eldest in the sample, had ceased sexual activity prior to the patient's diagnosis, only citing that sex was no longer a priority within their relationship; three couples had not resumed sexual activity, either because sex had not been a priority for the couple in the patient's overall medical recovery, or because the patient had not found a solution to their sexual dysfunction, but were physically intimate in other ways (e.g., cuddling, hugging, kissing); six couples had resumed various forms of sexual activity (e.g., mutual masturbation, oral sex, penetrative sex) working around changes to sexual functioning; and one couple declined to speak directly about their sexual relationship, so the state of their sexual engagement was unknown. Patients' reports of sexual dysfunction, including painful intercourse, difficulties with orgasm, decreased interest and desire for sex,

erectile dysfunction, vaginal dryness, and urinary incontinence interfering with sex were reflective of commonly reported changes to sexual function following surgical and adjuvant treatments for CRC (Averyt & Nishimoto, 2014; Hendren et al., 2005).

Similarly, patients' descriptions of altered body-image and loss of sexual identity were consistent with previous reports by patients regarding the notion of disfigurement by the stoma (Manderson, 2005; Ramirez et al., 2010; Reese et al., 2014; Vural et al., 2016). By including partners, the current investigation provided support for previous research conducted with patients alone that suggested that patients and partners' *both* experienced feelings of discomfort and disgust in relation to the stoma during sexual activities (Emslie et al., 2009; Manderson, 2005; Ramirez et al., 2010) and added to the minimal research of direct accounts from partners about their mixed reactions and perceptions of the stoma (e.g., Çakmak et al., 2010; Northouse et al., 1999; Persson et al., 2004). While some experienced initial worry upon learning of the stoma, the partners overwhelmingly expressed acceptance of the stoma and denied being bothered or 'turned-off' by the stoma during sexual or intimate moments. Only two patients expressed uneasiness around seeing the stoma or touching the colostomy bag when being intimate, but simultaneously maintained their acceptance of the patient and their body. Although this finding is hopeful, it is worth acknowledging that partners' emphasis on acceptance may be a reflection of impression management and social desirability within the context of the dyadic interview and/or a self-selection bias – that is, couples who are higher functioning and better adjusted may be more likely to participate in such research. Importantly, partners' expressions of uneasiness did not appear to be disruptive to the overall relationship functioning nor to the patients' self-image, perhaps because they shared similar beliefs about the colostomy as "strange" or "ugly" and/or because their ability to engage in honest conversation contributed to a sense of safety and

openness between partners. Patients' continued internal struggle with their body-image and sense of sexual identity despite partners' re-assurance in the current investigation is consistent with experiences of women after breast cancer (Kurowecki & Fergus, 2014) and suggests that patients may benefit from additional supportive counselling and/or education tailored toward body image.

This study confirms and extends previous research demonstrating that both patients diagnosed with CRC and their partners may have experienced preoperative sexual dysfunction, such that postoperative difficulties in couples' sexual relationship cannot be exclusively attributed to the cancer or its treatments (Traa et al., 2012b). Couples acknowledgement of pre-existing sexual concerns as well as their life-stage and age, as factors contributing to the changes in their sexual relationship – beyond or in addition to the cancer and colostomy – was considered adaptive in their adjustment. By way of identifying other reasons for these changes, in a process akin to re-attribution in cognitive restructuring (Cheung, 1996), the couple reduces the focus and blame on cancer which in turn supports at least some acceptance of the changes as more innocuous, inevitable fluctuations within the sexual relationship that are in keeping with what may be otherwise expected to naturally occur with age or stage of life.

The Pleasure-Relational Intimacy Model of Sexual Motivation posits that couples' valuing of intimacy and closeness with their partners as motivation for engaging in sexual activity, as opposed to being solely motivated toward sexual gratification, is supportive to their sexual adaptation after prostate cancer (Beck et al., 2013). In viewing sexual encounters as valuable for the closeness they bring, regardless of the degree of sexual pleasure, couples can remain hopeful and motivated toward sex even after a less than pleasurable sexual encounter. Relatedly, flexibility in couples' definitions of sexual activity, namely an expansion of the definition of sex beyond coitus ending in orgasm, has been associated with resiliency in couples'

sexual adjustment after cancer (Beck et al., 2013; Ussher et al., 2013). Couples' integration of different forms of sexual activity (e.g., masturbation, oral sex, use of toys, "rubbing") and an appreciation for other forms of physical intimacy (e.g., cuddling, hugging, holding hands) within the current analysis suggests that couples' willingness to re-arrange their sexual repertoires is also adaptive following CRC. Whereas couples who were focused on having sex as they had prior to the cancer did not see a solution to their sexual problems other than suffering through pain or having their partner seek sex outside of the relationship, those who expanded their thinking and behaviours beyond coital sex expressed more hope and acceptance of their sexual relationship. Similarly, the results of this study are consistent with previous research within CRC and cancer more broadly that couples' focus during treatment is on survival, and that sex may not become a priority until survivorship (Junkin & Beitz, 2005; Traa et al., 2014).

The results are unfortunately also reflective of an overall trend within oncological care of failing to educate patients and their partners adequately over the course of the cancer experience about coping with the sexual impacts of cancer and its treatment (Averyt & Nishimoto, 2014; Sporn et al., 2015; Traa et al., 2014). CRC patients and their partners, in particular, have expressed the need to have frank conversations with their health care providers about the possible impact of CRC on sexual functioning but also on the quality of the sexual relationship and psychosexual changes that accompany these physiological changes (Traa et al., 2014). Accordingly, they have also expressed the need to be informed of the treatment options for these concerns should they arise (Traa et al., 2014). A common barrier identified by health care providers to having such conversations is a lack of training specific to sexual health (Averyt & Nishimoto, 2014; Fitch et al., 2013). To this point, however, this study demonstrated that simply facilitating a conversation between members of a dyad about the sexual relationship holds the

potential to encourage learning between partners and foster new understandings of one another's adjustment process, even when couples report having open communication about sexual matters. A similar experience was described by Traa et al. (2014) following their facilitation of separate focus groups with CRC patients and their partners, in which they found that the format encouraged "in-depth exploration of sexual health care needs" (p. 771). Research supports that open communication between partners is supportive of their ability to adjust to illness and sexual concerns and, this self-disclosure can, in turn, be enhancing of relational intimacy (Badr & Taylor, 2008; Bois et al., 2016; Manne & Badr, 2009). Therefore, providing both individuals and couples with a safe space to discuss their sexual concerns related to CRC –without explicit guidance or solutions from a professional – may in and of itself hold therapeutic benefit for couples' adaptive sexual adjustment.

### **Limitations**

As this analysis was embedded within a broader study of couples' overall experiences coping with colorectal cancer and adjusting to life with a permanent colostomy, theoretical sampling (Glaser, 1978; Glaser & Strauss, 1967) was not possible. As a result, the primary limitation of this study is the homogeneity and size of the sample. The sample consisted of primarily heterosexual couples and only one gay couple. Thus, the current results are biased toward the sexual adjustment of heteronormative couples (i.e., partnership between cis-men and cis-women) and under-represent the sexual adjustment of gay, lesbian, and queer couples. The analysis would have benefited from additional representation of couples from the LGBTQ+ community; inclusion of sexual diversity would have provided a more representative and rich account of couples' experiences in sexual adjustment to a colostomy after CRC. In the current investigation, *avoiding flaunting function* was only mentioned by the gay couple who

hypothesized during the interview that sharing the same genitalia (i.e., both partners having penises) may have contributed to the partner's instinct to hide and feelings of guilt about his sexual function relative to his ill-husband. In addition, this couple emphasized several times that anal sex had never been a primary goal in their sexual repertoire prior to cancer, but imagined they would have had a significantly more difficult time in adjusting to the impact of the cancer and colostomy had anal sex been a central focus of their sexual pleasure. Research of gay couples' experiences after prostate cancer demonstrates distress over the loss of penetrative anal sex and prostate stimulation following radical prostatectomy (Hartman et al., 2014; Lee et al., 2015), so it stands to reason that the experience of erectile dysfunction in combination with the inability to use the anus as a penetrative source of pleasure following sphincter-sacrificing surgeries in CRC would be similarly distressing and therefore merits further investigation. The sexual health needs and concerns among sexual minorities during cancer care are distinct from those of heterosexual couples (Hill & Holborn, 2015), as is highlighted in the current investigation, and future research would benefit from including their perspective.

In addition, the sample lacks ethnic and racial diversity by consisting primarily of white/Caucasian participants. Inclusion of more ethnically and racially diverse participants would also have provided a more nuanced and rich account of couples' sexual adjustment experiences as sexual practices, attitudes, and behaviours vary across ethnic and racial groups (Cain & Mohr, 2003; Meston & Ahrold, 2010; Okazaki, 2002). Lastly, the sample consisted largely of male patients and their partners; including greater gender diversity within the sample may have yielded additional information about adjustment experiences across gender identities. Unfortunately, recruiting female patients and their male partners proved more challenging than recruiting male patients and their female partners. A study examining gender differences in

adjustment to CRC found that female patients with male partners reported lower relationship satisfaction than male patients with female partners and that males, regardless of their patient or caregiver status, provided less emotional support compared to females (Goldzweig et al., 2009). Relatedly, a systematic review of studies examining dyadic adjustment to CRC found that females, regardless of role status, tend to report poorer adjustment, higher short- and long-term distress, lower marital satisfaction, and more role problems (Kayser et al., 2018). This review also found that the majority of studies that included both patient and partner consisted of samples of male patients and their partners, suggesting this bias is a common though no less problematic limitation. It is possible that female patients and their male partners who agreed to being contacted by the study coordinator/first author but declined or failed to return phone calls ( $n_c = 9$ ) were experiencing more strain in their adjustment and relationship. Accordingly, such couples may have described a more tenuous sexual adjustment with additional challenges, if they had participated. The current sample consisted exclusively of non-distressed couples, according to the Kanas Marital Satisfaction Questionnaire (Ward et al., 1999; see Table 1), suggesting that the current account of couples' sexual adjustment to CRC and a colostomy may not reflect the experiences of couples who are experiencing relational distress.

A limitation of the analysis itself is that some defining properties are only endorsed by a minority of the sample (see Appendix A) suggesting that they may be less robust. This may be in part a consequence of the homogeneous and small sample as well as the fact that only portions of the interview transcripts were related to sexual adjustment. Additional material about couples' sexual adjustment, gained from full interviews specifically about sexual adjustment, would likely have yielded a more nuanced theory and perhaps more robust defining properties and categories (i.e., more couples endorsing each category/property). On the other hand, given couples did not



participate *specifically* to talk about their sexual adjustment, but instead their adjustment in general, the more process-oriented category wherein couples exhibited *varying willingness and readiness* to talk about their sexual adjustment was able to emerge from the data. Further research with larger sample sizes and in-depth examination of couple sexual adjustment after CRC with a colostomy should be conducted to provide confirmation or elaboration of the categories from the current analysis.

## **Conclusion**

The current investigation provides an account of couples' sexual adjustment to a permanent colostomy following rectal cancer, an experience that is severely understudied from the perspective of the dyad, despite consistent evidence of CRC patients' sexual dysfunction and distress. Couples described both cognitive and behavioural strategies for adjusting to both the sexual functioning and body image changes experienced by the patient, such that they were able to maintain an intimate connection, even, for some, without having sexual intercourse. That being said, these changes were still experienced as challenges to the sexual relationship and the patient's sexual self-identity. While couples may have been warned preoperatively of the potential for changes to sexual functioning, many described a lack of guidance and support from their health care team around the causes and prognosis of the physical changes as well as the available treatments and psychosocial supports for addressing their sexual concerns. The results point to the natural resiliency of couples to adjust to these changes, at least to some degree, and yet the need for health care providers to offer support to both patients and their partners around these concerns into survivorship when sex and intimacy may become of greater concern to the couple.

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### Chapter 3

#### **Study 2, An Exploratory Case Analysis of a Novel Internet-Based Intervention for Couples' Psychosexual Adjustment to an Ostomy After Colorectal Cancer**

Research indicates that sexual health is overwhelmingly ignored in oncology and that colorectal cancer (CRC) receives less attention in this regard compared to other site groups like breast and prostate cancers, despite sexual difficulties being common among men (5-88%) and women (50%) after CRC (Badr & Krebs, 2013; Falk & Dizon, 2020; Gilbert et al., 2009; Jonsdottir et al., 2018; Traa et al., 2012). While patients and couples may be warned by healthcare providers about the physiological changes to sexual functioning (e.g., erectile dysfunction, vaginal stenosis) caused by CRC treatments, acknowledgement of the psychosocial disruptions to sexual health (e.g., body-image, sexual communication, desire) and the provision of supportive care to address these are relatively rare occurrences (Averyt & Nishimoto, 2014; Maree & Fitch, 2019; Traa et al., 2014). Sexual distress is often a delayed impact of cancer, becoming a priority in survivorship when patients may have less frequent contact with health care providers (Carlsson et al., 2010; Junkin & Beitz, 2005; Traa et al., 2014), suggesting that these conversations are crucial when patients do visit their healthcare providers.

CRC patients and their partners have expressed a desire to have conversations with their health care providers about the sexual impacts of cancer and its treatment, particularly from a psychosocial perspective, as well as more education about the supportive resources and treatment available to assist their sexual adjustment (Traa et al., 2014). Accordingly, Cancer Care Ontario recently released guidelines for addressing sexual health in oncology. Notably, their most vital recommendation was that "...there be a discussion with the patient, initiated by a member of the healthcare team, regarding sexual health and dysfunction resulting from the cancer or its treatment. Ideally, the conversation would include the patient's partner, if partnered" (Barbera et

al., 2016, p. 8). As our previous research suggests, facilitating conversations between patients and their partners, even without providing any intervention or education may spur sharing and learning between members of the dyad and a deeper appreciation for each other's adjustment to CRC and the ostomy (Study 1). Despite the evidence for cancer-related sexual changes and a call for consistent conversations with patients and their partners, research suggests that fewer than one third of CRC patients are informed preoperatively of the risks to their sexual well-being (Chorost et al., 2000). These sensitive issues often go unaddressed in CRC treatment because neither patient nor healthcare provider feels comfortable broaching the subject (Averyt & Nishimoto, 2014). Patients report feeling uncomfortable raising this subject with their health care providers (e.g., fear of embarrassment, perception of overburdening the health care system) and would rather that clinicians initiate by offering information and assistance in this area (Averyt & Nishimoto, 2014; Dowswell et al., 2011; Traa et al., 2014). Clinicians, in turn, are hesitant to broach the topic of sexual dysfunction due to practical limitations in their service (e.g., time), perceptions that discussing sexuality is inappropriate, and lack of knowledge about effective treatment (Averyt & Nishimoto, 2014; Traa et al., 2014). When sexuality *is* addressed, patients report inadequate preparation from their health care providers about the sexual consequences of their CRC treatment, including unintentionally offensive responses or hopeful yet inaccurate information from clinicians (Averyt & Nishimoto, 2014; Dowswell et al., 2011; Hendren et al., 2005).

### **Psychosexual Interventions for Couples Adjusting to CRC**

Very few psychosocial interventions for the sexual adjustment of CRC patients and their partners in particular have been evaluated for their feasibility and efficacy. To our knowledge only two interventions have been studied. The first is a novel intervention developed specifically

for couples after CRC and the second is the application of an existing model of communicating about sexual health to this population. These two lines of research will be reviewed here.

Reese, Porter, Somers, and Keefe (2012) published a pilot feasibility study of a telephone-based intervention for couples to address physical intimacy and sexual concerns following CRC. As opposed to targeting a particular dysfunction, the goal of their intervention was to enhance intimacy. The intervention consisted of four 50-minute telephone sessions with couples. In these sessions, couples were provided with psychoeducation about the impact of CRC on sexuality, taught communication skills training (e.g., approaches to communicating, problem-solving, sharing exchanges), given instruction in cognitive restructuring to identify and challenge rigid and unhelpful thoughts about sexuality and cancer, and lastly, granted an opportunity to discuss activities to enhance intimacy. In the first session, couples were introduced to sensate focusing by Masters and Johnson (1970). Couples completed a graded series of sensate focusing exercises between sessions (i.e., touching above the waist, touching below the waist excluding genitals, touching below the waist including genitals). Additional homework exercises included reading psychoeducational materials, practicing a communication exercise, and engaging in an intimacy-building exercise, depending on the session's content.

Nine couples participated in the intervention (three living with colostomies and two with reversed ostomies) and completed pre- and post-treatment measures of sexual distress, sexual communication, intimacy, dyadic adjustment, and sexual function. Post-treatment, most couples (83%) reported the program quite helpful and quite easy to participate in, as well as important for couples coping with CRC. In terms of feasibility, results indicated that communication, sensual touching, intimacy-building exercises, and trying new sexual activities were perceived as most helpful and were most commonly used. In contrast, cognitive re-structuring was less commonly

practiced and regarded as one of the least helpful skills; the authors suggested that this is likely due to its complexity and time required to integrate as habit. As this was an uncontrolled trial with a small sample size, the authors qualified their results as only preliminary evidence of protocol's efficacy. Among patients, they found large effect sizes (Cohen's *d*) for reducing sexual distress and improving sexual communication, and only medium and small effect sizes for dyadic adjustment and enhancing intimacy, respectively. Interestingly, female patients showed a large effect size in improving sexual functioning, while male patients had little to no change in this area. Among partners, female sexual function had a large effect size again, while all other measures showed medium effect sizes.

Following their feasibility study, Reese et al. (2014) published a randomized pilot trial (RCT) of their intimacy enhancing intervention. In this study, ten couples completed the intervention while eight couples made up a waitlist control group. In addition, this study included a measure of sexual self-efficacy and the medical impact on sexual functioning for patients and partners. In terms of feasibility, the largest proportions of participants rated engaging in an intimacy-building activity as "quite a bit" helpful (90%) and easy (75%). Sensate focusing was used by most couples (95%) but was deemed as "quite a bit" easy and helpful by only around half of the sample. Due to the small sample size, significance tests between groups were not calculated; instead individual pre-treatment to post-treatment change scores were calculated for each participant and between group effect sizes were calculated as a measure of efficacy. Among patients, these analyses showed a large effect size for improvement in female sexual functioning as well as large to medium effect sizes for alleviating medical impact on sexual functioning and enhancing self-efficacy for enjoying sexual activity despite physical changes. Notably, there was no demonstrated effect for patients on levels of sexual distress or intimacy, and there were

negative effects on their sexual communication and the self-efficacy items related to communication and dealing with sexual difficulties. The authors propose that the negative effects may be due to ceiling effects and suggest screening for high distress at baseline. Among partners, analyses showed large effect sizes for increasing communication, male sexual function, and self-efficacy in the domains of communication and dealing with sexual difficulties but only a small effect size in female sexual function. As next steps, they propose a multi-site trial to attain a larger sample size and follow-up measures to study longitudinal effects. These two studies by Reese and colleagues (2012, 2014) demonstrate promising results suggesting that both CRC patients and their partners can benefit from interventions that target sexual concerns through the enhancement of intimacy and communication about sex. Moreover, their work demonstrates that delivering interventions in a way that minimizes patient burden (e.g., travel time) is particularly advantageous as a majority of couples in both studies reported liking the telephone-based nature of the intervention, with some reporting that the telephone was preferable to face-to-face sessions for convenience and comfort discussing such sensitive issues.

In another line of research on couple's sexual adjustment following CRC, Ayaz and Kubilay (2009) applied the PLISSIT model, developed by Annon (1981), to address the specific sexual concerns of individuals living with stomas following intestinal cancer or disease (e.g., colitis). The acronym PLISSIT represents four steps in an approach to intervening in matters of sexual health at different levels of intensity: Permission, Limited Information, Specific Suggestions, and Intensive Treatment. In their study, Ayaz and Kubilay (2009) met with patients and their partners in their homes for eight bi-weekly sessions. Sessions 1 and 2 focused on stoma care, physical problems, and changes to their lives and relationship as the initial Permission step of the model. In session 3 and 4, couples were provided education about the causes of sexual

concerns (e.g., mood, body image, impact of stoma on sexuality, changes to physical functioning) with regard to the Limited Information step of the intervention. During sessions 5 and 6, as part of the Specific Suggestions step, couples were given suggestions for addressing their concerns about (a) stoma products, (b) changes in mood (e.g., body image, anxiety), and (c) the impact of the stoma on their sexual interest and functionality. During the final two sessions of the intervention, they discussed changes to their sexual life and their relationship and suggestions for addressing their concerns were provided. The authors indicated that Intensive Therapy, the final step of the model, was not required by the participants as they were all sexually active by the final assessment time point and had no other sexual concerns that required outside referrals. A total of 60 couples participated in the study, equally divided between the intervention group and control group, however only patients completed pre- and post-measures of adjustment. Patients completed the Golombok-Rust Inventory of Sexual Satisfaction (GRISS) measuring avoidance, satisfaction, communication, non-sensuality, frequency of intercourse, vaginismus, anorgasmia, premature ejaculation, and impotence, at time points pre- and post-intervention or after four months of waiting in the case of controls. Total GRISS scores were significantly improved ( $p < .05$ ) for both male and female patients pre- and post-intervention and there were significant differences ( $p < .05$ ) between the intervention and control group on physical and emotional concerns; these results suggest that the PLISSIT model can be used to decrease sexual problems for patients with stomas.

### **Study Aim and Rationale**

While Reese et al. (2012, 2014) and Ayaz and Kubilay (2009) demonstrated promising results in supporting the sexual and intimate re-adjustment of couples after CRC through these step-wise or manualized approaches, both of their interventions required the commitment of

couples and a healthcare provider for four to eight sessions. From a practical standpoint, as time, labour, and privacy are limited within hospital settings and contribute to the lack of consistent conversations around sexuality and intimacy (Averyt & Nishimoto, 2014; Fitch et al., 2013; Maree & Fitch, 2019; McLeod & Hamilton, 2013; Traa et al., 2014), there remains a need to develop methods of addressing couples' sexual concerns, from a psychosocial perspective, in a brief and contained way that can be easily integrated into regular practice.

Accordingly, a novel two-session intervention was developed for the present study in an attempt to fill this gap in care. This intervention was a response to the call by Barbera et al. (2016) to have conversations with oncology patients and their spouses and was further inspired by our previous work suggesting that couples can learn about their adjustment to CRC during facilitated conversations (Study 1). At its basic core, the intervention was intended to provide couples with an opportunity to have conversations about the sexual and intimate changes they had endured. The format and content of the intervention also drew upon the work of Reese et al. (2012, 2014), by emphasizing intimacy through sensate focusing and delivering the program via the Internet. However, unlike Reese et al. (2012, 2014), the focus of the intervention was on enhancing couples' resiliency and thus was also informed by broader concepts and models of sexual and relational resiliency from research in sex therapy and oncology described further below.

Originally, the current study aimed to pilot the intervention but due to significant challenges in recruitment (see Study 3), only two couples completed the intervention. Nonetheless, their participation holds the potential to provide useful information on how couples respond to an intervention such as this, in a formative fashion. Thus, the intent of the current study was to make use of these couples' valuable contributions to research by conducting an



exploratory embedded single-case study of the two session intervention (Yin, 2018) – positioning the intervention as the ‘case’ and its components as the ‘embedded units of analysis’ – and using feedback from post-treatment dyadic interviews and questionnaires in combination with facilitator observations as sources of information. Results from the current study offer a contribution to the literature by providing an exploration of two couples’ experiences with a *brief* intervention designed to support an under-addressed aspect of CRC care. Moreover, from a program-planning perspective, results from this study may offer preliminary information about the acceptability and feasibility of the intervention from the perspective of its users, as well as ways in which the intervention may be improved for future research. As the intervention was designed with the hopes of one day being integrated into standard care at the host-hospital, the case-study design offered an additional advantage in that it allows for consideration of the context of the intervention.

## **Method**

### **Intervention Development and Description**

#### ***A Resilience and Strength-Focused Approach to Intervention***

Couples’ concerns around sexuality and intimacy are highly complex and nuanced, and manifest in idiosyncratic ways as a function of their individual and dyadic histories, their relational system (e.g., way of coping, communicating, making meaning), and their cancer-related challenges. Aiming to resolve each couple’s concerns about sexuality and intimacy within a brief intervention (i.e., one to two sessions), with pre-determined session content that addresses *all* possible concerns, is not realistic and would limit the ability to respond to the unique presentation of each couple. Thus, developing a 1 to 2 session sexual health intervention that can be integrated within standard practice in CRC care poses the challenge of balancing the

‘structure’ of the intervention, such that it can be learned and consistently applied across health care professionals, with the ‘tailoring’ of the intervention, such that it honours and acknowledges the unique concerns and dynamic of each dyad.

In an effort to strike this balance between pre-determined structure and tailoring, the current intervention elected to focus on couples’ resiliency as it applies to their sexual and intimate relationship. Instead of aiming to *solve* couples’ concerns about sexuality and intimacy, as in problem-focused or deficit-based interventions, the focus of this intervention was on enhancing couples’ relational strengths and resiliency such that they are better prepared to independently cope with these challenges or seek out additional supportive resources. To support this process, the intervention at a most basic level, provided couples with the opportunity to have professionally-facilitated conversations about the sexual and intimate changes they had experienced since the CRC diagnosis and ostomy surgery. To provide some degree of structure to the intervention, theories and exercises from couples’ and sex therapy more broadly were drawn upon as ‘conversational scaffolding.’

In particular, the intervention was informed by research demonstrating that a couple's sense of mutual identity or ‘We-ness’ is supportive of their resilience – or ability to adjust to and accommodate major life changes, including cancer (for example, see Ahmad et al., 2017) – and that couples can build awareness of their mutual identity and relational strengths through professionally-facilitated conversations (Ahmad & Reid, 2016; Fergus & Reid, 2001; Fergus & Skerrett, 2015; Reid et al., 2008; Reid & Ahmad, 2015; Singer & Skerrett, 2014; Skerrett, 2015). Additionally, the intervention incorporated an exercise based on the Physical-Pleasure Relational-Intimacy Model of Sexual Motivation (PRISM) which proposes that couples that value sex for relational intimacy and not only physical pleasure are more resilient to sexual

changes imposed by cancer and its treatment (Beck et al., 2013). The exercise involves each partner plotting their motivations for engaging in sex on a dimensional matrix from high to low for each dimension of motivation (i.e., physical pleasure and relational intimacy) to facilitate couples' dialogue about their reasons for having sex (Beck & Robinson, 2015). The exercise has demonstrated success in this regard as a component of couples-based psychosexual interventions for couples following prostate cancer (Hampton et al., 2013) and breast cancer (Cullen, 2019), in combination with psychoeducation, other behavioural exercises and goal setting. Lastly, consistent with the tenants of the PRISM model, the intervention included sensate focusing by Masters and Johnson (1970) as a means of encouraging intimacy between partners; this exercise was well-received by participants in Reese et al.'s (2012, 2014) intervention, providing further support for its inclusion here. For a fulsome discussion of the theoretical underpinnings of the intervention as well as a detailed description of the session content, see the intervention manual in Appendix B. For brevity, only an overview is provided here.

### ***Intended Intervention Users***

The intervention was designed to be delivered to: (1) patients who had undergone surgery for a temporary or permanent ostomy (i.e., colostomy, ileostomy) as result of treatment for CRC and reported a subjective change in their sexual and intimate relationship with their partner as a result of the cancer and/or ostomy; (2) couples in any length of relationship and couples of any gender identity and sexual orientation; and (3) couples at a minimum of 1-month post-active treatment, when couples were thought to be more likely to be interested in addressing matters of sexual health. The intervention was *not* intended for couples wherein one or both members of the dyad is currently experiencing mental health concerns that would reasonably interfere with their ability to engage in the intervention (e.g., suicidality, active psychosis, substance abuse, spousal

abuse, etc.). Lastly, due to practice restrictions by the College of Psychologists of Ontario patients and partners participating in the intervention must be 18 years of age and reside in Ontario, as well as be proficient in English (speaking, reading, and writing).

### ***Intervention Format and Delivery***

The intervention consisted of two 1.5-hour sessions conducted with both members of the dyad (i.e., patient and partner) and was delivered via online video conferencing platform Vsee. Vsee is an application-based videoconferencing platform that is free to download from the Internet and commonly used by professionals practicing telemedicine. A pre-treatment questionnaire was also completed online by each member of the dyad via LimeSurvey prior to the first session. Email was used to share session materials (e.g., educational information, instructions for activities) with couples' consents.

The decision to deliver the intervention online was based upon the advantages that online modalities offer in reducing barriers to therapeutic participation (e.g., travel to hospital, cost of parking, increased ease in discussing sensitive topics) (Richardson et al., 2009; Simpson & Reid, 2014), the knowledge that patients in early recovery from ostomy surgery prefer to be close to home (Danielsen et al., 2013; Persson & Hellström, 2002), and the positive feedback from couples following participation in a telephone-based sexual intervention after CRC that suggested a preference for alternatives to in-person sessions (Reese et al., 2012, 2014). The delivery of psychotherapy through Internet based platforms is quickly becoming more common and has demonstrated the efficacy and feasibility comparison to in-person therapy (Richardson et al., 2009). Moreover, online delivery has been successfully adopted in previous psychosexual interventions in cancer (Cullen, 2019; Fergus et al., 2015; Kang et al., 2018).

Sessions were scheduled one week apart to allow couples to complete exercises between meetings with the facilitator. The intervention was facilitated by the first author (Molly McCarthy), a doctoral candidate in Clinical Psychology, who has research experience with the target population and additional clinical training and knowledge in couple's therapy and sexual functioning. Sessions were delivered under the supervision of Dr. Karen Fergus, a licensed psychologist with over 20 years of experience in psycho-oncology and counseling couples affected by cancer, as well as experience in the development and evaluation of online interventions.

**Pre-Treatment Clinical Questionnaire.** Prior to the first session, couples independently completed a questionnaire about their sexual and intimate concerns related to CRC and the colostomy. The questionnaire included open-ended questions about their current physical and emotional concerns in relation to their sexual and intimate relationship. It also included a computer adapted version of the PRISM model sexual values plotting exercise (Beck et al., 2013), which instructed participants to plot their motivations for engaging in sexual activities from their own perspective and assuming that of their partners' perspective. The pre-treatment questionnaire was designed to be clinically useful in reducing time for information gathering and completing the PRISM exercise *during* the session with the facilitator.

**Session One.** The first session focused on facilitating a dialogue between partners around their concerns related to sexuality/intimacy since the patient's cancer and ostomy surgery. Couples were encouraged to discuss how their current concerns around their sexual and intimate relationship were similar to or different from their pre-morbid sexual and intimate concerns, and how they have coped with these challenges. Discussions aimed to help couples make their assumptions about their adjustment and coping explicit and relational strengths were identified

by the facilitator as they arose. Responses from their pre-treatment questionnaires informed the facilitation of this conversation and relevant psychoeducation about sex after cancer and with an ostomy was provided as the discussion unfolded. Following this general discussion, each partner's responses from the PRISM exercise were presented to the couple to facilitate a conversation about sexual values. Psychoeducation about the PRISM model and the adaptive advantages of valuing intimacy was provided. The session ended by introducing the couple to a sensate focusing exercise (Masters & Johnson, 1970), referred to as a “mindful touch” exercise, with the rationale that sensate focusing can enhance intimacy and facilitate the re-integration of sensual touch, without the performance pressure of sex. The couples were encouraged to try the first step of sensate focusing at least once prior to the following session; problem-solving around potential barriers to engaging in the exercise were discussed prior to ending the session. Following the first session, written educational materials and instructions for sensate focusing were emailed to couples.

**Session Two.** The focus of the second session was to continue the conversation around couples' sexual relationship, consolidate learning, and look toward the couple's ongoing adjustment on their own. The session began by facilitating conversation around the couples' experience with the sensate focusing exercise. Couples were asked to share their perspectives as both givers and receivers of touch and encouraged to explore the ways in which sensate focusing related to their typical ways of being intimate. Following this discussion, couples were encouraged to continue their dialogue from the first session and relate any learning that occurred about their relationship, their partner, or themselves them. The facilitator encouraged this discussion by summarizing the content from the previous session and by identifying, as a third-party, the relational strengths observed in the couple during the first session. Lastly the session

ended with a goal setting exercise to encourage consolidation of learning and the creation of shared goals in their sexual adjustment. The facilitator worked with couples to complete the commitment to change form, adapted from Lockyer et al. (2001) and employed by Hampton et al. (2013), based upon their learning during the two sessions (see Appendix C). In the current intervention, this exercise was named “promises to ourselves” as opposed to “commitment to change” to convey and encourage acceptance in cases when couples did not meet their goals. After the second session, a document with the couple’s goals or “promises to ourselves” was emailed to them with their consent.

### ***Confidentiality and Security***

All couples were made aware of the potential risks of corresponding via email ahead of being sent study materials and links to LimeSurvey questionnaires. VSee is a secure, encrypted videoconferencing software commonly used by health care providers practicing telemedicine. VSee software it is managed by a peer-to-peer architecture, such that video is streamed directly from end-point to end-point, and is neither intercepted, recorded, nor stored by the server. Although VSee software includes a feature for video-recording sessions, this option was not used. Sessions were instead audio recorded using a digital audio recorder, in the same manner that in-person counseling sessions are regularly recorded. As video recordings of sessions were not necessary for effective supervision, priority was placed on optimizing privacy and confidentiality by using audio recordings only.

### **Study Design**

An embedded single-case study as defined by Yin (2018) was undertaken. The intervention was considered the ‘case’ and main focus of inquiry, and the ‘parts’ or core characteristics of the intervention (i.e., the two sessions of facilitated conversation, the

intervention exercises, the online delivery, facilitator) were considered the ‘embedded units of analysis.’ Couples’ post-treatment interviews and questionnaires as well as the facilitator’s observations were the sources of information about the intervention (and its embedded parts) as well as its context. In the current analysis, the intervention case was considered to be bound within the context of the online environment as well as the host hospital from which couples had been recruited and treated.

Given the novelty of the intervention, the purpose of the case study was exploratory (Baxter & Jack, 2008; Yin, 2018). An exploratory approach was preferred at this stage of the intervention development because it provided an opportunity to investigate how couples responded to the intervention and its various components as well as ways that the intervention protocol may be improved from the perspective of its intended users. In this way, the exploratory case study can serve a formative role in the program development. In particular, the case study addressed the question: “How do couples receive (i.e., experience and perceive) this novel brief sexual health intervention?”

## **Procedures**

### ***Selection of Couples***

The two couples contributing to the embedded case study of the intervention are a convenience sample and represent the two first couples from the population for which the intervention was designed, to have completed it. One couple was referred by their ostomy nurse while the other self-referred via an information sheet shared online by a local ostomy organization. Couples were screened by the intervention facilitator to ensure they met the criteria of the intended user (described above).



### ***Post-Treatment Program Satisfaction Questionnaire***

One month after completing the program, each member of the dyad independently completed a post-treatment program satisfaction questionnaire. The questionnaire solicited feedback related to their experience with the program (e.g., overall satisfaction, convenience, helpfulness, online component, favourable and unfavourable aspects of in program, interaction with facilitator) and suggestions for improvement. See Appendix D for full questionnaire.

### ***Post-Treatment Interview***

One-month following the completion of the program, couples also completed a dyadic interview pertaining to their experience with the intervention. Couples were asked open ended questions about (1) their overall impressions of the program, (2) their satisfaction with the intervention activities (i.e. PRISM, educational material, sensate focusing, and goal setting), (3) their experience in working with the program facilitator, and (4) the advantages and disadvantages of the online delivery of the program. The intention of the post-treatment interview was to solicit feedback from couples about their experiences and perceptions of the program as well as potential ways of improving the intervention. The 45-60 minute interviews were performed by another member of the research team (Ruth Vanstone) and were audio-recorded using a digital audio recorder. See Appendix E for semi-structured interview protocol.

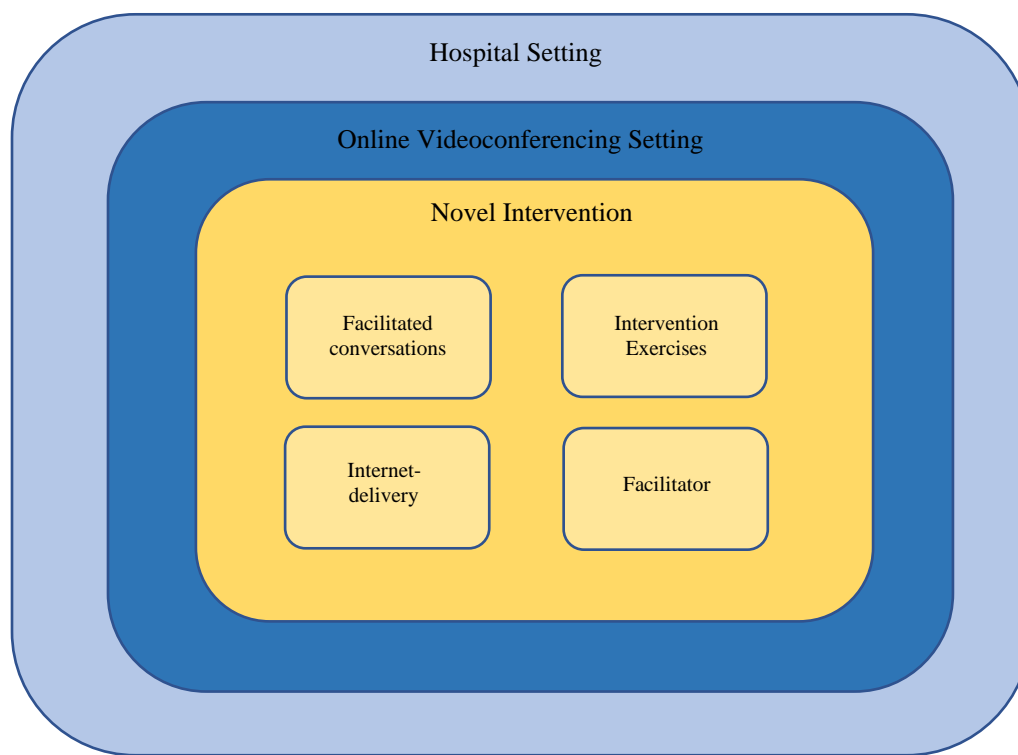
### **Methodology and Analysis**

Being that the case study was exploratory in nature, as opposed to using theoretical propositions to guide the analysis, a descriptive or conceptual framework was selected as the analytic strategy (Baškarada, 2014; Baxter & Jack, 2008; Yin, 2018). The framework was based on the organization of the intervention, consisting of core characteristics and bound in a context (refer to Figure 3). Questions, specified below, were then developed to guide the analysis of the

core characteristics of the intervention while considering how the intervention's context may have influenced couples' experiences with and perceptions of the intervention.

**Figure 3**

*Conceptual Framework for Case Analysis*



First, the transcripts of the dyadic interviews and then the individual post-treatment satisfaction questionnaires were read from beginning to end with a focus on the couples' and individual's experiences with and perceptions of the intervention as a whole and of the following core parts or characteristics of the intervention: (1) the two sessions of facilitated conversation, (2) the intervention exercises (i.e., PRISM exercise, mindful touch, promises to ourselves, written educational material), (3) the online delivery of the intervention, and (4) the facilitator. Using N-vivo for Mac Version 12 for data management, information relevant to each of the units

of analysis were grouped together, according to the descriptive framework, in order to more easily identify themes (Miles & Huberman, 1994). The following research questions were used to guide the coding of themes in this exploratory analysis:

1. What were the couple's (or individual's) experiences in relation to this aspect of the program (or the intervention as a whole)? How does the couple (or individual) describe their engagement with, or response to, this aspect of intervention (or the intervention as a whole)?
2. What is the couples' (or individual's) perception of this aspect of the program (or intervention as a whole)? How does the couple (or individual) feel and think about this aspect of the program (or the intervention as a whole)?
3. In what ways did context appear to influence couples' (or individual's) experiences or perceptions of this aspect of the program (or the intervention as a whole)?

A constructivist orientation was assumed during the analysis, consistent with Yin (2018) and Stake's (1995) epistemological stance in case analysis and reflecting a belief that each couple, and each individual within the couple, would have their own truths and realities about their experience participating in the intervention. Accordingly, memoing was used during the analysis to track similarities and differences in participants' experiences and impressions of the intervention both within and between couples as means of comparison (Stake, 1995). Moreover, as a way of managing the subjectivity of the first author who led the analysis – and who was both the facilitator and co-developer of the intervention – memoing was used to track notable instances wherein the first author held a different reality of an experience than that described by the couple (or individual) or when the couple (or individual's) experience was consistent or inconsistent with the intended design of the intervention as described in the intervention manual

(Appendix B). As such, the facilitator's observations – as a participant-observer of the intervention with the two couples – were jointly included as a source of data. Given this epistemological stance, the structure of the case study results is comparative in nature (Yin, 2018).

### **Participating Couples**

Two couples completed the intervention and provided feedback about their experience. The following is a description of both couples. Identifying information including names, dates, ages and other potentially identifying details have been altered and some additional information may be fabricated to protect the identity and privacy of the participants. Changes to these details are inconsequential to the analysis and results of this case study.

#### ***Couple 1: Eli and Tess***

Tess contacted the study coordinator/facilitator by phone after she viewed the study advertisement circulated by an ostomy organization. The coordinator provided Tess and then Eli with the study details and conducted the telephone screening with each individually. They were deemed eligible and taken through the informed consent process. At that time, both self-endorsed changes to their sexual and intimate relationship since Eli's diagnosis of CRC and unexpected ostomy surgery as a result of a complication in his treatment approximately six months prior. His doctors had not been able to confirm whether the ostomy would be reversed or whether it would be permanent. Tess and Eli were struggling in their adjustment during this uncertain time, both individually and relationally.

Eli, 56, and Tess, 64, were married for 25 years. They described pre-existing sexual problems prior to Eli's cancer. Both reported difficulty in their physical sexual functioning and a disparity in libido, with Tess desiring more intimate and sexual contact. They described the

ostomy as compounding these premorbid problems. Eli reported changes in sexual functioning and interest following his ostomy surgery, which he attributed to his cancer treatments. He also described worry about leakage and fear that Tess would be disgusted by the stoma.

***Couple 2: Rita and Hugh***

Rita was referred to the study coordinator by the ostomy and continence nurse at Sunnybrook Health Sciences Centre. When contacted by the coordinator, Rita and her husband, Hugh, expressed a desire to participate, were screened and deemed eligible, and taken through the informed consent process.

Rita, 72, and Hugh, 80, had been married for 5 years. Rita had been diagnosed with rectal cancer and received a permanent colostomy five months prior to participation. Both Hugh and Rita indicated that they were experiencing challenges in their physical sexual function, with Rita's occurring as a consequence of her cancer surgery. Rita was also concerned with her physical appearance in relation to the stoma, feeling less attractive since this change. She described worry about engaging in sexual activity with Hugh because of the appearance of the stoma and the idea of having the ostomy bag between them. She also reported fear of injury during sex and sadness over the loss of spontaneous sex. Since she had not been initiating sex, Rita wondered whether Hugh might feel unwanted.

**Results**

The following results are presented according to each of the embedded units of analysis – facilitated conversations, intervention exercises, online delivery and facilitator – and then related back to the intervention case as a whole. Each section compares and contrasts information from the various informants and sources of data.

## Facilitated Conversations

Both couples reported positive experiences of the two sessions of professionally facilitated conversations about their sexual and intimate relationship. When asked during the post-treatment interview about their expectations of the sessions prior to beginning them, Rita reported that she expected that during the sessions, “we would have to talk and not necessarily like the things we were talking about, or maybe just feel a little uncomfortable talking about those things, but that’s okay. Sometimes discomfort is necessary for progress.” She and Hugh agreed that her prediction about the sessions was true, but Rita also explained that talking about sex and intimacy is “never really totally comfortable, but she [referring to facilitator] did a good job of making us comfortable”. Otherwise, Rita and Hugh reported no other expectations about the sessions or intervention as a whole but described themselves as curious to find out what the process would entail. Hugh, in particular, had an open attitude upon beginning the sessions, “[I] didn’t know what to expect, didn’t go in expecting miracles, didn’t have high expectations or pre-suppositions of what was going to happen.” Similarly, Tess and Eli reported no incoming expectations about the intervention. In fact, they expressed surprise but appreciation for the counselling they received during the facilitated sessions,

Eli: Well, like I thought it was just gonna be sort of a research thing, so I was kinda surprised that it actually helped us.

Tess: Yeah, like we didn’t know it was kind of...she is kind of like a therapist, a marriage therapist, the way she was talking to us, so we didn’t, that was kind of a bonus, because we know this was research to see if something should be offered to people after they have the operation [referring to ostomy surgery] to help them and so we knew that, but you know the helpfulness of the counselling was nice.

Despite the facilitator’s provision of all steps of participation, including the intention to evaluate a novel psychosexual intervention for couples and a description of the intervention itself

– including that they would be receiving the intervention – it appeared that Tess and Eli did not fully comprehend the purpose of the study. This suggests room for improvement in terms of expectation setting for the intervention, specifically within the context of the trial. This finding was particularly surprising to the study coordinator/facilitator who completed the informed consent with this couple, as it was incongruent with their apparent understanding of the study purpose and procedures (including the two-session intervention) during this process. That being said, this apparent disconnect may be a function of the language used by the facilitator when presenting and describing the intervention (i.e., “an opportunity to have facilitated conversations about the changes you have experienced in your sexual and intimate adjustment and explore your strengths as a couple”) which deliberately did not include terms like “counselling” or “therapy”, as the intervention was not intended as psychotherapy, but which are terms that – evidently – appear to be applied by couples to describe it.

Both couples reported that the opportunity to have facilitated conversations about their sexual and intimate relationship was beneficial in encouraging their communication. As Eli expressed, “A couple of times I felt on the spot about answering questions, but they were important to ask... [the facilitator] asked questions that allowed us to be honest and confront issues that may have developed into a problem.” Hugh and Rita also agreed that they spoke about aspects of their relationship and adjustment that they would not have otherwise. Rita wrote in her post-treatment satisfaction questionnaire that she appreciated the facilitated conversations “sparked more open communication after the formal sessions.”

The idea that the facilitated conversations allowed for new understandings of each other and themselves was common feedback across the two couples. For Eli, who described difficulty

expressing his emotions and being easily overwhelmed by those of his wife, the facilitator was instrumental in reaching mutual understandings during difficult discussions. He explained,

[Facilitator] had a way of defusing the conflict, you know? We were having some trouble between us and she was able to interpret things that we're not able to interpret ourselves, so you know when we're expressing our feelings about the frustrations with the ostomy and things like that, I think she was able to interpret things a little better so that each of us could understand each other... We were able to express ourselves and then she was able to sort of, you know, pause enough to sort of regurgitate what we were saying and then put it out in a different way so that Tess can understand what I was saying, and I can understand what Tess was saying.

This couples' pre-morbid sexual tensions made it difficult for them to communicate and come to an understanding about how the ostomy was interfering with the patient's sexual desire and initiation currently. In his post-treatment satisfaction questionnaire, Eli wrote that he had gained an understanding of his wife's feelings about his ostomy, while Tess wrote in hers that she had learned more about her husband's "thoughts on intimacy, especially how bad he feels about his own body".

Rita, the other patient in the sample, echoed Eli's sentiment that the facilitator aided her in finding the right words to express herself. For Rita, the opportunity to voice her experience aloud during the facilitated conversation was beneficial to developing self-understanding, as she explained "it's helpful to vocalize things because it kind of makes you organize your words and think about what you want to say and therefore you can get a better grasp on how you're feeling as an individual once you vocalize something." Accordingly, Rita's husband Hugh described having a greater understanding of his partner's difficulty with regard to the ostomy as a result of the sessions. For Hugh, the facilitated conversations led to deeper understandings through listening to Rita respond to questions from the facilitator, particularly with regard to her sexual self-identity after changes to her body due to the ostomy,



I liked listening to Rita's response to a lot of the questions, because it gave me some insight into how she feels about things... the greatest thing that I got out of [the sessions with the facilitator] was that any question that [the facilitator] posed or suggested, Rita opened up to it quite easily and expressed her feelings, and I learned a lot from that. I learned a lot about her.

Rita and Hugh agreed that the intervention as a whole had brought them closer together, both in their understanding of one another and their sense of being united in their adjustment efforts, as they explained

Rita: It just made me focus on the fact that [Partner] and I are together on this. I probably wouldn't have felt that so much if it hadn't been for the intervention.

Hugh: I agree with that. I think it solidified—not solidified but further enhanced our understanding of each other and our closeness.

While this couple identified the facilitator as important to this process, Rita also indicated that she believed the sessions went smoothly due, at least in part, to their willingness to “share and open up” which she believed made the facilitator's “job easier”. She predicted that if couples were less willing to express themselves, the sessions would be more difficult to complete.

The couples differed in their feedback about the length and number of sessions with the facilitator. Tess and Eli reported that they would have preferred to have a greater number of sessions that were shorter in length. In particular, Tess indicated that the length of the sessions was “draining” and too long to maintain her attention and that at one point during the first session, she found herself drifting off to sleep. This was also observed by the facilitator. She suggested that the sessions should be one hour in length, as opposed to 90 minutes, and that the two sessions should be followed up by a third session one month later. Eli agreed, explaining that having more sessions might have allowed for more opportunity to develop a therapeutic alliance with the facilitator and engendered more comfort in his ability to discuss matters of sexuality and intimacy. This couple reported that they were motivated toward working on their sexual and

intimate relationship when they were in the midst of the two session program, but that once their sessions had ended and they got “back to the grind of life”, their “little spurt of enthusiasm was stunted”. They explained that having a follow-up session, one month later would have helped to maintain their motivation through remaining accountable to a third-party. On the other hand, Rita and Hugh reported that they did not feel they required additional sessions with the facilitator, as Hugh summarized, “I thought the whole program was well done, I thought that it left us with goals, and I don’t think you could have elaborated much more on what was—what the content was.”

## **Intervention Exercises**

### ***PRISM Exercise***

While none of the participants identified any of the exercises as uninformative or unhelpful, unfortunately only Tess and Eli provided feedback about the PRISM exercise specifically. Eli described the exercise as “enlightening” and a helpful beginning point to their discussion,

It is actually a good thing as a starter, because then you kind of go into it with a better attitude... A little bit more, you know, a little bit more knowledgeable attitude about what’s going on with your partner, instead of, you know, I can only think about what’s going on with me. I don’t know exactly what’s going on with Tess and how she’s feeling about it.

While Tess felt she expresses her feelings clearly, Eli explained that he can feel “overload[ed]” by her emotions and that the exercise helped him to better understand them. Tess indicated that her take-away from the exercise was that it “showed like you can have different thought patterns about each other”. That being said, she was relatively less enthusiastic about the value of the exercise, describing it as “not horrible” but “okay”, because from her perspective the theory underlying the exercise was reductionistic and not reflective of the complexity of her experience,

“... it just didn’t really resonate that well with me... It just seemed too kinda out there, too vague or something... too simplistic.” Tess’s response is consonant with her premorbid sexual dissatisfaction and difficulty; her response suggests that the PRISM exercise may only capture *part* of couples’ experiences, particularly among those in higher distress.

### ***Mindful Touch***

Both couples agreed that the mindful touch exercise was valuable, but it was not without its difficulties for either couple. Eli expressed that the mindful touch was a “good starter exercise” and in his post-treatment satisfaction questionnaire wrote that he “plan[s] to develop it enough to once again have a sex life”, viewing it as “foreplay” and “a good ice-breaker” to sex. Tess, for her part, agreed that the exercise was valuable in that “it felt good...it was pleasant, it was nice... to be touched again and [in] such a tender way” but recalled that it also resulted in some tension as she had had to initiate the exercise, as she had done for most of their intimate encounters, and that Eli had been frustrated that “...it wasn’t going to go further”. For Rita and Hugh, the exercise was challenging, in part due to its structure, but also because of Rita’s discomfort with her body since the ostomy. Rita explained that the preparation involved in order to begin the exercise took away from her enjoyment,

...it’s almost like when you see on TV these couples who are trying to have a baby, and they look at the calendar and they take temperatures and all those things seem to make it—take something away from the enjoyment of the moment. And I think that, you know, wrapping up my stoma, and turning off the lights and saying, ‘Okay, here we go’—it just didn’t make me feel comfortable, especially when Hugh’s in the living room watching TV and I look at my watch and I say, ‘Okay, what do you think?’... [Should] I turn off the TV and the rest of the lights in the house?... So, no, we just weren’t comfortable with that.

Hugh agreed, saying “...it almost feels like it’s—not a chore, but it’s—something that you *have* to do, not *want* to do... [when] you bring something into it that seems to be mandated by somebody else, it’s tough to get into it.” He explained that they lead busy lives and with his own

health issues, it was easy for them to come up with excuses to put off the mindful touch exercise. When the couple did attempt the exercise, they explained that they didn't "follow the instructions to a T" as Rita "found 20 minutes was too long, so we agreed maybe shorten it a bit, but still it seems so... planned and structured". Despite their reservations, they were able to adapt the exercise to their comfort level and, Hugh described an unexpected way of growing their intimacy through humour about the exercise:

The good thing about it is we laugh at each other sometimes when we just touch and— [say] '[Facilitator] wouldn't like that' or '[The facilitator] would like that' [laughs]... her suggestion of the exercises gave us a bit of a laugh with each other... a comfort level, [though] we haven't actually done the exercises as per se.

Interestingly, both couples perceived enough value in the mindful exercise to incorporate it in their goal setting or "promises to ourselves" exercise, though neither followed through.

### ***Promises to Ourselves***

Both couples completed the goal setting exercise at the end of the second session and were provided with a written copy of their goals via email. When completing the exercise, Rita, a self-described overachiever, suggested they call the exercise "good ideas for ourselves" as opposed to "promises for ourselves" to reduce the pressure of performing, while Hugh appreciated that the intervention left them with goals in mind. As previously mentioned, Hugh and Rita had agreed that they would continue to practice the mindful touch exercise, specifically, they planned to attempt it without any clothing as a way of easing Rita back into physical touch in the nude. During the post-treatment interview one-month later, they had not followed through on this "good idea" partially because Rita did not feel comfortable uncovering herself and partially because of their busy lives, as explained by Hugh, "a large impact of what happens after the program is where we are in our personal lives, where we are in our health situation, [family] situations—we have a lot going on in our life." That being said, Rita did follow through on one

“good idea” that she could do on her own; she had planned to sort through her clothing and to donate or otherwise get rid of the items that were not supporting her sense of well-being in her body since the ostomy. She also planned to seek out new clothing that might make her feel more comfortable presenting herself to the world - in her case, clothing that concealed the ostomy appliance, and enhanced her sense of attractiveness. She recalled having this idea prior to the intervention but had not felt confident in her plan until validated by the facilitator, “I had sort of thought of that on my own—I mean, outside the session, but to hear [the facilitator] talking about it when I brought it up... [I thought], ‘Yeah, my idea’s pretty good!’” Rita indeed followed through with her plan after the end of the intervention, and while it did not lead to the intended outcome in the way she had hoped, it nevertheless led to a positive ending and long-term change, as she described,

...throwing away some of the old clothes made me feel like, ‘Oh, I spent so much money for this and now I can’t wear it.’ ...[then] I went online [but]...it made me depressed to look at all the ugly clothing there is to wear for people with ostomies and [the] clothing was really unsuitable, because it was very restricting. And I looked at that and I thought, ‘You know what, this isn’t helping me at all.’ ... However, it did lead to my thinking, ‘You know what? I can do just as well shopping for myself online or in the stores and buy just regular clothing.’ So, it was kind of a double-edged sword. I feel better with better-looking clothing, and it [lifts] me to have new clothes anyway... [I’m] buying clothes that are more suitable for my lifestyle now... That’s probably one of the most helpful things to me... it’s become part of my second nature now.

Like Hugh and Rita, Tess and Eli had also planned to continue with the mindful touching. They had intended to do the exercise at least once per week and for Eli to initiate it. While Eli reported that he had raised the idea of trying the mindful touch exercise once or twice since ending the intervention, he explained that it was “never the right timing” and that he had been preoccupied with his personal adjustment to the stoma, stating “good intentions don’t always come through... I have to admit I’ve been distracted with stuff that’s going on... either work or the issues I’m having with the stoma, so it hasn’t really made me think about having an intimate relationship.”

Tess agreed that their plan “[got] lost in the day-to-day” and re-emphasized that additional sessions would have been helpful in this regard, as she explained “if we had a third session it would be really top of mind that we want to do something that’s good for us. But anger and resentment and drudgery and tiredness, you know, can easily take their toll.”

### ***Educational Material***

Patients, Eli and Rita, reported reading all of the educational material, while both partners, Tess and Hugh, reported reading only some. Eli, having read all of the educational material, rated the information as adding “quite a bit of value” to the intervention but felt that the sessions with the facilitator were much more valuable. For Rita, it also appeared more valuable to speak to the facilitator. Rita rated the educational material as being of only “some value,” explaining “there wasn't much information. It did help to review it with the therapist, which facilitated a better understanding of the material, and more in-depth discussion.” Partners were also left wanting more than the reading exercise. While Tess agreed with her husband that the educational material added “quite a bit of value” and was “interesting and informative”, she felt that it was long and that “it would have been more motivating to have to do something in addition to the reading”. Hugh felt similarly about the reading exercise, as he explained, “I’m not a huge reader of material. [I] choose to learn from verbal exercises.”

### **Online Delivery of Program**

The couples had very different experiences with and impressions of the online delivery of the program, particularly with regard to their perceptions of the online platform as secure and private. Both couples were informed about the use of LimeSurvey and Vsee during their screening and informed consent process. As part of this discussion, the use of Vsee as a secure and private platform designed and regularly used for telemedicine was explained by the

facilitator/coordinator. Eli and Tess completed the program fully online; they completed the pre-treatment questionnaire via LimeSurvey and two-sessions of facilitated conversation via VSee. Neither raised any concerns regarding privacy during their participation and during their post treatment interview, Tess remarked when discussing the use of Vsee, “It was nice to know that it’s a privacy thing too. That it’s secure.” On the other hand, Rita and Hugh had significant concerns regarding the privacy of VSee once they downloaded the program, to the extent that they refused to complete the two sessions with the facilitator via the platform. On the day of their first session, approximately 10 minutes prior to the start, Rita called the facilitator about a security concern. She indicated that she had received an email from Facebook, for which she had an account associated with her email address, stating that she had received a direct message from a stranger. Because she had received this email from Facebook in the days following her download of VSee and prior to her first session, she understood this email to mean that this unknown individual as well as her friends on social media were aware that she was participating in the study intervention and would be able to view the online sessions. While the study coordinator assured Rita and Hugh that Facebook was in no way associated with the study or VSee and that their information had not and would not be shared with others, they expressed that their privacy concerns could not be allayed. Rita described the timing of the emails as “too coincidental” in her post-treatment interview and, while in the post-treatment interview Hugh conceded to not be as “technical” on the computer as Rita, he believed that the emails were “red flags that this [VSee] is not a secure site.” Given these “red flags” Rita and Hugh indicated that they were no longer comfortable completing the two sessions via VSee but they would participate in-person. This request was accommodated. In the post-treatment interview, Rita summarized the experience,

[Meeting in person] was better than doing it online because of the security concern that we had since I started getting all kinds of funny emails after, you know, I signed up for the website—I forget the name of the program [referring to VSee]—but to do this kind of thing online, so that was a little unfortunate, but okay. And it was [nice] that we could be accommodated to the point where we could drive in and meet face-to-face.

Despite their distrust of VSee, Rita and Hugh completed their pre-treatment questionnaire via LimeSurvey, continued to consent to email communications, and expressed an openness to the potential of participating in an online intervention in the future if they felt it was secure. Similarly, this distrust of VSee did not appear to impede their ability to engage in the two in-person sessions. This being said, they expressed preference for in-person therapy over online modalities. In considering how context may have shaped their perception of the online platform, the larger geohistorical context, not previously included in the descriptive framework at the outset of the analysis (see Figure 3) was brought to light as, near the time of this couple's participation, the CEO of Facebook was being questioned about privacy breaches of users' data to Cambridge-Analytica (Wichter, 2018).

For Eli and Tess, who participated in the two-sessions via VSee, the online delivery of the program was advantageous for several reasons. Both partners perceived meeting online to be convenient by avoiding the “drag” of the commute to the hospital and the cost of parking. They also expressed that the online modality was flexible in that they were offered session dates and times that were best suited to their schedules, as Eli recalled in the post-treatment interview, “It wasn’t just like, ‘Okay well I have an open slot here.’ So it [referring to online format] really worked well for us in terms of timing and comfort.” Moreover, they found VSee as a software easy to use, as Tess described, “It took only one click and we had good visual and good sound.” That being said, Tess and Eli explained that they had a new computer with a large, high definition screen and good audio system, and cautioned that other couples without such hardware



may not have as seamless of an experience using the videoconferencing software for the two sessions. When asked about the perceptions of completing the sessions online as opposed to in-person, as in traditional visits with healthcare providers, Eli and Tess differed in their opinions. Tess expressed the notion that nothing was lost in completing the sessions online as opposed to in-person and again made reference to the convenience of the online delivery, “there’s hardly any difference... I love it actually... it basically saves us an hour.” Eli on the other hand, had mixed thoughts and feelings about completing the sessions at home as opposed to in-person, comparing his experience in the online intervention to the individual in-person psychotherapy that he was concurrently seeking. He described the impact of being comfortable in one’s home when discussing sensitive topics, “It’s very comfortable. We’re able to be in our own space to, you know, feel comfortable talking about stuff,” and contrasted this with the greater risks in self-expression that he feels he can take when outside of his own space,

...there’s something about sitting in a therapist’s office and in their chair and, you know, there is something about being outside of your element that you’re able to, you know, be a little bit more liberal with what you’re discussing... You know, sometimes [...]—you know, as much as we [count it out], it is nice to be in your own space and stuff like that, sometimes if you take yourself outside of that space, some of your barriers are taken down a little bit.

While Eli acknowledged that being alone during his in-person therapy, as opposed to with his wife, may similarly free him up to being more open, he felt strongly that the setting contributed to feeling “more liberal” in his expression.

### **Facilitator**

Both couples reported similarly positive impressions of the facilitator and identified qualities of the facilitator that are supportive of a therapeutic alliance. The facilitator was described by the couples as: “relaxed but professional”; “caring and perceptive”; “empathetic”; “well-prepared”; “a careful listener”; having a “good memory”; and making them feel “we were

her total focus”. The facilitator was also described by Eli as “fair” and able to “interpret answers in a meaningful way” so that he and Tess could come to better understand one another. Hugh and Rita similarly agreed that the facilitator was able to ask questions and offer reflections to both clarify and elaborate their discussion, while also providing “stability and focus” to the sessions. Hugh was most appreciative of the facilitator’s ability to make him feel at ease, as he recalled, “I think the greatest attribute for me was that she made us feel comfortable. And I think that’s very important in that kind of a situation when you’re dealing with very personal issues with someone you don’t know.”

In addition to encouraging communication and understanding, the couples reported that the facilitator’s specialized knowledge provided an opportunity to receive psychoeducation specific to their medical situation. Rita reported that she did not “recall talking about, or anybody talking to me about [the medical specific] in the hospital, so [the intervention] helped fill in some of those gaps” and was an aspect she liked most about the intervention. In fact, the facilitator’s knowledge of their specific medical situation as well as knowledge of the sexuality and psychosocial adjustment was regarded as essential by Tess, as she explained,

I would say if you’re gonna do this for people... that it’s really key that you have that kind of high standard person and not just ... somebody who has qualifications but not really the understanding. Like you need all of the components for people to relate over a computer screen... There’s lots of people that don’t know anything [or] enough about Eli’s situation to be helpful... And obviously [the facilitator] knew exactly what was going on, so from both—all sides, medical side, she knew a lot about the ileostomy of course and then the whole sexuality, communication... it has to be a person that has all of those things.

For Tess, this knowledge was instrumental to engendering “faith” and “trust” in discussing these issues with the facilitator, as she did not have to “go and ask somebody.”

## Overall Impressions and Experience

Both members of each couple reported overall satisfaction with the intervention as a whole and reported that they would recommend the program to other couples in their situation. Rita reported that while she knew the program was in an early stage of development that “as a participant I didn’t really feel that this was brand new, it kind of looked like you’ve been doing your thing for a while, so it was very well planned out and thought out.” Rita also expressed appreciation that the intervention offered the opportunity for she and Hugh to do something *together* during their adjustment but did suggest that other couples may be hesitant to complete the program due to the time commitment. In fact, for Rita, the idea that other couples might also need a program such as this a significant part of her learning, as she explained:

I think, for me the most helpful thing is to realize that I’m—I’m or we, are not unique. There must be a lot of people in our situation, first of all for a program like this to have been developed, and then in discussions I recognized that that’s—I’m of the same opinion, that there are a lot of people who are in this situation. And that was helpful to me, because I didn’t feel so alone.

For their part, Eli and Tess reported having sought out several different counsellors throughout their marriage yet Tess reported that the current program was particularly helpful “because it [came at] such an unsettled time in our lives with lots of stress and fear of the future of my husband’s condition... so more was at stake.”

Unfortunately, both couples expressed that adjusting to the ostomy is a difficult process and that the hospital did not, in their views, offer enough support around their adjustment. Eli and Tess were the most vocal in their expression of disappointment at the level and quality of support they had received from their healthcare team in helping Eli to adjust both practically and emotionally to his unexpected ileostomy. Tess, as the caregiving partner, also felt her emotional well-being was largely ignored by Eli’s health care providers. While they expressed appreciation

for the intervention, they were also realistic in conveying that intimacy and sexuality is only one part of adjustment after an ostomy for which they need more support, as Tess put it:

[The intervention] is very specific and it's great, but yeah, the learning curve for people when they just let you loose with stuff [referring to ostomy] without giving you a lot of information was pretty bad at [Hospital].

Importantly, as evidenced in their feedback about the intervention exercises, the patients' abilities to engage in the exercises appeared to be impacted by their degree of adjustment to the ostomy. Their degree of practical and emotional adjustment to the appliance appeared to influence their capacity, motivation, and interest in prioritizing their sexual and intimate adjustment within their overall coping. Moreover, body image and confidence since the changes imposed by the ostomy was also identified by the patients as a challenge in their sexual adjustment and for Rita, her willingness to engage in the intervention exercises at all. This lack of support in the host-hospital setting reflects the primary way that the context of the hospital appeared to impact the couples' experience of the intervention; against the background of their perceived lack of overall support at the hospital, the couples viewed the intervention as helpful, and yet their continued challenges in adjustment given the lack of support from the hospital affected their ability to fully engage in the intervention.

As was expected, given the purpose of the intervention, both couples reported that while there was benefit to the program, their concerns were not resolved by its end. As Tess replied when asked whether she felt better able to cope with the sexual and intimate changes,

I can't lie and say, 'Oh yes, this solved everything.' What it did was give us a little burst of, 'Oh yeah, let's try this, hey!' but then we fell back on what's been happening in the last year, which is very un-sexual.

Rita echoed these sentiments when she described her take away from the program as a whole,

I've still got issues [related to sexuality and intimacy], so that's something that maybe time will take care of. But at least I'm focusing on making an effort. Thinking about what

I—what might be some good things for me to do, but it's—it's not like this session waved a magic wand over me and cured my feelings... There may be—they may be diminishing, like I said to Hugh the other day... 'you know, I'm not so focused on this bulge I've got on me now.' And maybe that's because I got some clothes that are bulge-concealing... so I think the main thing for me is time, with some of the things that we talked about [during] the intervention in the back of my mind.

That being said, the intervention appeared to give Rita hope, as she wrote in her post-treatment satisfaction questionnaire, "I am still very self-conscious about [the ostomy but] I think that if we continue the exercises, we will eventually be able to overcome that." Rita and Hugh also agreed that the intervention had not improved their sexual relationship specifically but was beneficial to their relationship as a whole, as Hugh explained, "I think sexually it hasn't—I don't think it's helped us that much. But emotionally between ourselves I think it certainly has given me a great deal of insight and admiration for Rita...for me it's almost strengthened our relationship."

For both couples the intervention resulted in referrals to other resources. During the post-treatment interview, Tess and Eli requested a referral to a couples' therapist for counselling as they continued to experience relational distress. For Hugh and Rita, the request for support came during the second session when Rita requested a referral for individual work and some resources for a relative. During the post treatment interview, Rita recalled her gratitude for the resources:

[The referrals] helped because it just took a little bit of my load off and I don't know what it meant for [the facilitator], a phone call or two, but whatever it meant for her that was—that made me feel better that she took that bit from me.

During either post-treatment interview, both Tess as a partner and Rita as a patient reported that they were unaware prior to the sessions with the facilitator that they could access psychological services through the hospital. Of course, it impossible to know whether the couples would have otherwise reached out to another health care provider for these psychosocial supports, had they not completed the intervention.

## **Facilitator Reflections**

As the facilitator of the intervention, I maintain my own experience of the intervention as completed with the two couples. This section provides a brief overview of my reflections about facilitating these sessions.

Rita's suggestion that the intervention may have been easier to deliver with a non-distressed couple or couples that are more reluctant to communicate was consistent with the facilitator's own experience, especially with regard to the more exploratory and open-ended dialogue of the facilitated conversation component. Rita and Hugh, although they did not participate online, exhibited several relational strengths and examples of a 'We' orientation within the dynamics of their relationship which meant that the task of identifying relational strengths was much easier than with Tess and Eli, who were more relationally distressed and appeared to face greater challenges in their communication.

As facilitator, the online environment was both convenient and inconvenient. Within the context of the trial, the facilitator attempted to be as flexible as possible in accommodating the couples' schedule and the online modality, which eliminated travel to the host hospital, increased her ability to accommodate evening sessions with the couple who participated virtually. That being said, this level of accommodation may not be possible among regular HCPs at the hospital. At the same time, the online environment required the facilitator to take additional time to trial the connection prior to the appointment at the request of one of the patients. Additional time to help familiarize couples with the online platform should be considered in the implementation of the intervention, and is a potential drawback of the Internet-delivery for future facilitators with busy schedules or limited administrative support – especially when considering that this extra time was spent with the couple who ultimately refused to participate online.

Completing the PRISM exercise within the virtual environment was also experienced as challenging by the facilitator. Namely, the inability to easily review the visual plot with the couples complicated the facilitator's ability to clearly share their responses with the couple and relate their answers to the theory underpinning the PRISM. A screen-sharing functioning within the virtual platform would have improved the facilitator's ability to review this exercise.

### **Discussion**

The current study provides an exploration of two couples' experiences and perceptions of engaging in a brief intervention for dyadic psychosexual adjustment to an ostomy after CRC. The outcome of the analysis provided several avenues for future development for the program, as well as preliminary information about the program's acceptability and feasibility by its intended target population. Feedback about specific aspects of the program (i.e., two sessions of facilitated conversation, intervention exercises, online delivery, facilitator) as well as the program as a whole were analyzed and suggested varied experiences of the program within and between couples, but overall positive impressions.

Both couples reported positive experiences with the facilitator and their sessions together. They identified the facilitator's expression of empathy (e.g., warmth, reflection, listening), a process that has been associated with therapeutic alliance (Nienhuis et al., 2018) and outcome of traditional psychotherapy (Wampold, 2015), as a positive attribute of their interaction with the facilitator. However, the couples' feedback also suggested that expectations around the intervention – another common factor in psychotherapy associated with outcome (Wampold, 2015) – could have been more clearly set during the informed consent process for the research, as despite best efforts by the facilitator and thorough discussion of the consent form, there appeared to be a misunderstanding. In terms of intervention development, this finding implies

that the intervention protocol may benefit from being more explicitly named when it is offered by facilitators, as part of a pilot trial or in a clinical context, similar to other couples-based interventions in oncology (e.g., ‘CoupleLinks’ see, Fergus et al., 2015). Within the sessions, the couples identified the role of the facilitator as valuable in providing guidance and focus and encouraging deeper understanding and elaboration between them, which is consistent with positive feedback from couples that completed a six session Internet-delivered psychosexual intervention for breast cancer (Cullen, 2019). Importantly the couples identified that the facilitator’s specialized psychosocial and medical knowledge were instrumental in her effectiveness as a facilitator, specifically in normalizing their psychosocial concerns as related to the ostomy and cancer as well as instilling confidence in the intervention through her ability to appreciate and speak to the challenges of adjusting to an ostomy without seeking out assistance from others. Previous online psychosexual interventions for cancer patients have been facilitated by a mental health professional alone, or as part of a team that included a physician (Cullen, 2019; Fergus et al., 2015; Kang et al., 2018). While the facilitator did not provide medical direction in the current intervention, the couples’ feedback suggests that its facilitators need to be skilled in mental health generally as well as well-informed about the medical and psychosocial aspects of cancer and ostomies to be perceived as credible by the couples. Accordingly, professionals with mixed education in medicine and mental health are likely most suited toward the role of facilitator in the current intervention, for instance mental health professionals (e.g., registered psychotherapist, social worker, clinical psychologist, clinical health psychologist, psychiatrist) with education related to psychosocial adjustment to cancer and ostomies.

Couples’ feedback about the various intervention exercises demonstrated preliminary information about of their acceptability by couples and feasibility to complete. That being said,



the couples' descriptions of their engagement with the exercises, particularly the mindful touch exercise, suggested that couples will complete the exercises in adherence with the instructions from the facilitator only to the degree that they feel ready and comfortable. Feedback from one couple who perceived the mindful touch exercise as too contrived or structured suggested how this perception might be additionally reinforced by ostomy hygiene or covering that must be done first. Previous studies have reported on the success of integrating the exercise within in-person group interventions for couples after prostate cancer (Hampton et al., 2013) and Internet-delivered psychosexual interventions for couples following breast cancer (Cullen, 2019) but, to this author's knowledge, this study is the first documented use of the PRISM exercise with couples following CRC. Unfortunately, only one of the couples reported directly upon their experience with the exercise, and they had mixed opinions about the value it added to the intervention. Feedback on the educational material suggested that it may be beneficial to integrate time within the second session to verbally review the educational material with the couple to enhance their understanding or to provide video-based or interactive ways of delivering the same information to better support different learning styles. Overall, however, couples had positive impressions of the intervention exercises, with none reporting that any of the exercises were unhelpful or of no value at all.

One couple refused to participate in the sessions with the facilitator due to their perception that the online environment was not secure, raising a significant concern about the acceptability of the online delivery of the program by its intended users. Despite the facilitator's best efforts to assure the couple of the security features of the telemedicine system, the couple could not be convinced otherwise. Use of online platforms for the delivery of psychotherapy is becoming more common because of its lower cost and ability to reach patients in remote

locations (Richardson et al., 2009) and has been successfully used in other psychosexual interventions for breast, prostate and gynaecological cancers (Cullen, 2019; Fergus et al., 2015; Kang et al., 2018), however it is not without its drawbacks. Patients' security and privacy are among the main legal and ethical challenges presented by use of technology for service delivery (Richardson et al., 2009). Unsurprisingly, patients' trust in a telemedicine portal for rehabilitative care is found to be largely based on their perception of control and privacy within the online environment (Van Velsen et al., 2015). Both patients and healthcare providers must trust that the technology itself is secure and protecting their data (Mair et al., 2007). In this couple's case, technological literacy appeared to contribute to the couple's misperception of Vsee as an untrustworthy program. Although they reported in the post-treatment interview that the program was easy to use, their refusal to participate via the online platform appeared to be related – at least from the perspective of the facilitator and clinical supervisor – to erroneously linking communications from an unrelated social media website (Facebook) with the initiation of the couple's Vsee account due to their close timing, leading to the incorrect belief that others could view their data without their permission. Technological literacy is of particular concern among older populations (Narasimha et al., 2016), and should perhaps be more carefully considered in further developing the program, given the majority of Canadians diagnosed with CRC are over 50 years old, with additional risk as age increases (Canadian Cancer Society, 2019). Upon review of the literature, Vsee has also been shown to have significantly worse usability ratings than some of its counterparts among patient users aged 60 and above, suggesting alternative telemedicine systems may be considered in the future (Narasimha et al., 2016). Moreover, credibility of a telemedicine system is in part related to the patient's perception of the healthcare professional (Mair et al., 2007), with qualities of competence, reliability, and responsibility

contributing to patients' perceptions of professionals as trustworthy (Van Velsen et al., 2015). As the facilitator and couple had had little interaction and thus opportunity to develop a trusting relationship prior to the first session, this unfamiliarity may have also contributed to the unsuccessful attempts of the facilitator to repair their trust once their perception of the telemedicine application was tainted.

This being said, considering the geohistorical context in this case analysis illuminated how larger social narratives may impact couples' experiences and impressions of the intervention, particularly if the intervention techniques or delivery are new and/or foreign for the couple. One can also argue that the couple's critical outlook of their social media privacy and the security of the online platform was not without cause, given Facebook was being investigated for breaches in privacy on the world stage (Wichter, 2018). While this larger scale context was not originally included within the conceptual framework of the current analysis, consideration of its potential influence within this case study suggests that future facilitators of the intervention and other Internet-based healthcare initiatives may benefit from taking into account how social narratives within the larger context may negatively impact couples' sense of comfort in the online environment (particularly with respect to discussions about such personal topics), and address these concerns as proactively as possible. It may be wise in future applications of the current intervention to spend more time during the consent process with couples to review the security of the online platform and provide education about the technology and security features. If possible, conducting this meeting in person, when the couple is at the hospital may help to engender more trust in the facilitator and in turn the telemedicine system (Van Velsen et al., 2015).

The couple that did participate online had mixed feedback about the online environment. Both partners agreed the online platform had easy usability and offered convenience that traditional in-person visits with a healthcare professional does not. However, the patient in this couple indicated that while he liked the comfort of being in his own environment during the sessions, he believed that he may have been more open and less guarded in an in-person environment at the hospital, for the very reason that he is outside his home. This notion is inconsistent with literature review of patients' experiences of eTherapy that acknowledged that patients may respond differently to the online environment but identified a number of studies reporting that patients felt less intimidated and safer to disclose their concerns openly in this context compared to in-person therapy, in part because patients felt a greater sense of personal space and increased personal control when meeting the therapist online (Simpson & Reid, 2014).

While both couples agreed that they continued to struggle with concerns related to their sexual and intimate relationship since completing the intervention, they had mixed feedback regarding the length of the intervention. One couple was satisfied with the number of sessions while the other reported that two sessions was insufficient for maintaining their motivation toward change. Given the time constraints on staff in the hospital setting as a major barrier to addressing psychosexual concerns in oncology, the aim of the novel intervention was to provide brief support to couples as previous interventions for this population were between 4-8 sessions in length (Ayaz & Kubilay, 2009; Reese et al., 2012, 2014). For this reason, the goal of the intervention was explicitly not on *resolving* couples' concerns, but instead focused on opening up conversation between partners and identifying couples' strengths in support of their self-efficacy in addressing their concerns. The couples' feedback provided preliminary support that the intervention, though not resolving couples' concerns, did contribute to learning about one

another, their sexual and intimate relationship, and shared strengths, as was intended. That being said, during the post-treatment interview one month after the intervention, the couples largely denied following through with their goal-setting exercise and having a better sense of coping with their situation. Therefore, future development of this intervention may consider inclusion of additional sessions, altered session lengths, or follow-up sessions to further support couples' prior to leaving them to cope independently. Ultimately, however, the program resulted in referrals for various mental health supports for each of the couples based on the content covered in the two sessions with the facilitator. Thus, the intervention may also be conceptualized as a stepping-stone for couples in accessing longer-term psychosocial supports when needed. Certainly, the couples reported a general sense of wanting more instrumental and psychosocial support around the ostomy from their health care team at the hospital and their degree of adjustment – or lack thereof – to the ostomy appeared to influence their engagement in the novel intervention. Therefore, the program may be one way of filling in gaps in CRC and ostomy care specific to intimacy and sexuality while simultaneously facilitating the coordination of resources through the provision of relevant referrals, with each potentially enhancing the other.

### **Limitations and Future Directions**

The current investigation is most limited by the small number of available participants. The embedded single-case study design provides an account of two couples' experiences and impressions of the program, but only preliminary information about the program's feasibility and acceptability. Given the nascent stage of the program and its novelty within CRC care in general, the current in depth study of two couples' experiences was informative with respect to understanding specific ways in which couples experience and engage with the intervention and in turn, identifying aspects of the intervention that may be targets for future program

development to better serve its target population. However, no trends or program outcomes can be evaluated through the current analysis and it is certain that the experiences of the two couples do not reflect *all* possible impressions of the program. Furthermore, the analysis was limited by use of only data sources from couples and observations by one facilitator, who was also a developer of the intervention; the inclusion of other sources of data, such as a formal post-treatment interview with other facilitators or quantitative outcome measures would have provided an even greater depth of understanding and opportunity for validation through the triangulation of data sources (Stake, 1995; Yin, 2018).

Next steps in the program development would ideally include a re-attempt at a pilot study of the intervention with a larger sample size, and random assignment to a waitlist control arm. Couples' completion of baseline, post-treatment and follow-up outcome measures related to sexual and relational satisfaction and functioning should be included in the design in order to evaluate the efficacy of the intervention in supporting couples' adjustment. Similar post-treatment interviews could be included in a mixed methods approach to capture further qualitative feedback of couples' experiences and perceptions of the intervention in order to gain more reliable information about the acceptability and feasibility of the intervention from the perspective of its users. Consultation with other health care professionals who work with the target population of the intervention about the results of the current analysis may also be of benefit to better understand how the specific intervention may be integrated within ongoing supportive care practices for CRC within the hospital. While limited, the current results suggest potential for this novel intervention to fill a gap in CRC care within the host hospital related to patients' and partners' sexual and intimate adjustment to an ostomy.

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## **Chapter 4**

### **Barriers to Recruitment**

#### **Original Intent of Study 2**

The original purpose of Study 2 (presented in Chapter 3) was to conduct a pilot randomized control trial of the novel brief Internet-delivered intervention to assess its feasibility, acceptability, and preliminary efficacy. The original goal of the project was to recruit a minimum of 20 couples who would be randomly assigned to either an intervention group ( $n = 10$ ) or a waitlist education group ( $n = 10$ ). The intervention group would receive the online intervention immediately, with sessions booked approximately one to two weeks apart. Those assigned to the waitlist education group would receive only the written education from the online intervention about sexual health and colorectal cancer (CRC) and would be given two weeks to read it. It was planned that participants in both groups would complete measures at baseline, post-treatment (i.e., following the two session intervention or the two week period to read educational materials), and at 1- and 3-month follow up. Couples in the intervention group would also complete a dyadic interview and questionnaire about their experience and impressions of the intervention at 1-month post-treatment.

#### **Recruitment Strategies and Outcomes**

The primary means of patient recruitment for the intended pilot trial were self-referral through posted advertisements and referrals from health care providers (HCPs). A number of efforts were made to reach patients and their partners via these avenues over the course of 12 months. Unfortunately, ultimately only two couples consented to participate.

Study flyers (see Appendix F) were posted within the hospital and shared with relevant organizations. The flyer was essentially a short-information sheet about the study and directed

interested individuals to contact the study coordinator through phone or email. Within the cancer centre, the flyer was posted in the waiting area of the gastrointestinal cancer clinic where patients would wait prior to all appointments with their surgical oncologist; in the waiting area of the radiology department and within the offices of radiology staff; in the waiting area of patient and family support; in the private offices of social workers and psychologists working with patients diagnosed with CRC; in the offices of the ostomy and wound nurses; in the Patient Education and Research Learning Centre, where patients and families can go to access educational information and research resources; and in elevators. On the host hospital's website, the flyer and study information were also posted on the gastrointestinal departmental page and trial registry. Attempts were also made to have the flyer reach a wider audience of couples in Ontario through sharing the flyer with ostomy and cancer organizations and requesting that they share the information with their networks. The flyer was sent by email either to the general email address or to direct representatives of the following organizations: Ostomy Canada Society and all of its regional support groups in Ontario, Screen Colons Canada, Canadian Cancer Society and all of its regional divisions in Ontario, Colorectal Cancer Canada, Gilda's Club (GTA), Wellspring Cancer Support Network (all locations), Cancer Care Ontario, the Canadian Association for Psychosocial Oncology, the Canadian Society for Enterostomal Therapy and the online peer support network meetanostomate.org. The majority of organizations responded and indicated that they would post the flyer within their centre/organization or share with relevant electronic mailing lists; Ostomy Canada Society posted the flyer to their social media webpages and website; some emails went without a response, despite a follow-up contact; and only one leader from an ostomy peer support group refused to share the flyer, with no reason provided despite follow-up attempts. Interestingly, the website director of meetanostomate.org (i.e., 'meet an

ostomate', a peer support network and forum for individuals with ostomies and their families, requested a \$500 advertisement fee in return for the sharing the flyer with the group's electronic mailing list of over 10,000 members and was firm in this request despite the explanation that this was a no-cost resource for couples and a not-for-profit project. Due to a lack of funds and uncertainty about the proportion of the mailing list that would meet the trial inclusion criteria at that time (e.g., living with a permanent ostomy due to CRC), this avenue was not pursued. One of the couples who ultimately participated learned of the study when the partner in the couple read the flyer sent to her via an ostomy organization and contacted the study coordinator.

The flyer was shared on social media by the study coordinator directly. A Facebook page for the study was created and approved by the hospital's Communications and Stakeholder Relations department. The study flyer and any updates to the study were posted on the page. The Facebook page for the study was also used to interact with the pages of ostomy organizations active in Ontario. There were no inquiries from couples via the Facebook page. The flyer was also shared via the popular social media website, Reddit. This website allows registered users to upload content to share and discuss with one another and is community-based, with users creating "subreddits" or pages on the website where content and discussion is centred around a specific topic. The coordinator shared the study flyer and information to the following subreddits: r/ostomy, r/cancer, and r/colorectal. The majority of publicly posted responses to the flyer were from Reddit users inquiring about the eligibility criteria, specifically why patients needed to have a cancer diagnosis and why patients who had colostomies or ileostomies for other reasons (e.g., inflammatory bowel conditions) were excluded from the study. Two individuals contacted the study coordinator directly via email in response to the posting on Reddit. In the first case, the patient was interested in participating but was ineligible because he resided in the



United States. In the second case, the partner contacted the coordinator but denied experiencing any distress within their sexual and intimate relationship, wanting instead to share her positive adjustment experience with the coordinator but expressed that she thought there should be specialized resources available for supporting couples after ostomy reversal, a procedure her husband was scheduled to have soon.

The study coordinator/facilitator also reached out to patients directly with the study information. The study coordinator/facilitator presented about the project at the hospital's annual education day for individuals living with an ostomy; no patients contacted the coordinator following this presentation. In addition, participants from Study 1 (presented in Chapter 2) – those who inspired the development of the intervention – were contacted about this new phase in the research program. These couples had provided verbal consent to the facilitator/coordinator during their participation to be contacted at a later date about publications stemming from the project and about future opportunities to participate in research. Six of the 11 couples were contacted; the remaining five were not contacted either because they had not consented to be contacted or due to their unwillingness to discuss sex, a premorbid unactive sex life, or a known cancer recurrence during Study 1. None of the previous participants who were contacted consented to participate; three of the couples had resumed a healthy and happy sex life, one couple cited time as a barrier, one patient had sadly passed away, and another couple failed to respond to follow-up contacts but reported continued sexual distress.

Several attempts were made to network and connect with other HCPs in the hope that they could facilitate patient referrals to the study. It was planned that the ostomy nurse at the cancer centre would act as the primary HCP facilitating referrals to the study because she meets with all patients scheduled for ostomy surgery. In the planned referral process, the ostomy nurse

would identify potential participants among her current and former patients and contact them by telephone to inform them about the study or inform them about the study during their next visit. Interested patients could then give permission to the ostomy nurse for the study facilitator/coordinator to contact them with more details and to conduct the eligibility screening if interested. The ostomy nurse had previously acted in this capacity for Study 1 (presented in Chapter 2); she had been very active and intrinsically motivated in this role and had strong relationships with her patients. In recognition of her role in the referral process, the ostomy nurse would receive co-authorship on future publication(s). Unfortunately, the nurse retired prior to the recruitment phase of the pilot trial. While her replacement agreed to take on this responsibility, she was less able to commit time to research in her role which limited the couples that might have otherwise been recruited through this avenue. The new ostomy nurse referred 14 couples to the study coordinator, with only one couple ultimately consenting to participate.

Two other HCPs were engaged in assisting with referrals, with the agreement of co-authorship on future publication(s). The first professional was a radiation therapist with training and interest in sexual health who had also assisted in recruitment for Study 1 (presented in Chapter 2) in a more secondary role. For recruitment in the pilot trial, the radiation therapist shared the study flyer with her professional networks, including the Cancer Care Ontario's Sexual Health Community of Practice and referred one patient to the study coordinator/facilitator. Unfortunately, this patient had planned active treatment for several more months, so was ineligible for the study. The second professional who was engaged in the recruitment process was a surgical oncologist. At the recommendation of the retired ostomy nurse, the study coordinator/facilitator contacted the surgical oncologist to inquire about his interest in assisting with recruitment in exchange for co-authorship. He agreed and requested that

the facilitator email him on a weekly basis following his post-operative gastrointestinal clinic in order to prompt him for patient referrals from the day's clinic (i.e., names of patient who had expressed verbal consent for more information and/or screening by study coordinator). The first week the surgical oncologist provided two referrals; no other referrals were provided by the surgeon on subsequent weeks. Neither of the two referred patients agreed to participate, with one couple failing to respond to follow up contacts after initially agreeing to participate and the other patient refusing to provide a reason for declining.

Other attempts were also made to reach out to other HCPs within and outside of the host hospital. The study coordinator/facilitator made two presentations to nurses in the gastrointestinal and genitourinary clinics about the study; all nurses were invited but only two nurses attended the first presentation and three attended the second. The study coordinator/facilitator also conducted walk-throughs of the gastrointestinal and genitourinary departments to introduce herself and the study to medical staff. As follow up, the flyer was shared electronically with both of these departments. One nurse working in these clinics subsequently provided a referral, but this patient was not eligible to participate because he was undergoing active treatment. The coordinator/facilitator was also invited to present to the entire radiology department; six medical staff attended and the study flyer was shared via email with the rest of the department. No referrals later came from individuals in the department. Lastly, the study facilitator met with a nurse working in the Sexual Health and Recovery Clinic (SHARe) at the cancer centre, a clinic for women with breast or gynaecological cancer, who informed her that she had not been referred a patient with an ostomy for several years and recommended that the facilitator reach out to Community Care and Access Centres. With the assistance of the wound nurse at the cancer centre who reached out to her colleague at the Toronto Central

Community Care and Access Centre the facilitator requested the possibility of nurses working with ostomates after cancer be allowed to provide them with a study flyer but repeated follow-ups went unanswered. To spread the word to staff both inside and outside of the hospital, the study coordinator/facilitator: attended the 14<sup>th</sup> Annual Surgical Oncology Education Day the host hospital, where attendees included medical staff from around the province; presented about the intervention at the Canadian Association for Psychosocial Oncology to both solicit feedback from other researchers/clinicians but also to inform them about the opportunity for their patients to participate; and completed an interview about the study with the an advisor from the host hospital's Communications and Stakeholder Relations department which resulted in a post published on *Your Health Matters*, the host hospital's blog. It appears these efforts resulted in one referral as the partner of a patient with an ostomy contacted the study coordinator after having been informed of the study by a nurse in the urology clinic at the hospital her husband was attending for sexual rehabilitation in a neighbouring city to the host hospital. In the end, the couple decided to focus their time on his care in the urology clinic and opted not to pursue the study intervention.

Two additional recruitment strategies were pursued but ultimately abandoned due to time limitations and privacy requirements. The first of these was an attempt to recruit patients at another hospital. The radiation therapist who was assisting with recruitment connected the study coordinator with her colleague from the Cancer Care Ontario's Sexual Health Community of Practice, a social worker at another hospital in Ontario. This social worker was interested in providing the study flyer to her patients, as appropriate. However, we were informed that this would require Research Ethics Board (REB) approval from her employer. The types of permissions, privacy training, and study requirements demanded by the hospital's REB were

particularly stringent and above and beyond the requirements at the host hospital or university. After several months of correspondence with the REB, with several delays in receiving answers, this avenue of recruitment was unfortunately terminated due to time limitations, despite the work that had been involved in preparing and revising the REB application. The second approach was an attempt to have the study coordinator/facilitator present in the gastrointestinal clinic during the surgical oncologist's post-operative clinic day. This strategy was recommended by an expert sexual health clinician researcher in prostate cancer who shared that his team has the most success in recruitment when a research staff member is present in-person to receive referrals from frontline medical staff in real time (A. Matthews, Personal Communication, February 8, 2019). In investigating the logistics of this recruitment strategy, the study coordinator/facilitator and supervisor met with the Patient Care Manager who raised concerns related to privacy (e.g., process of approaching patients, private space to meet with patients), which led to a meeting with representatives of the host hospital's REB and Privacy Office who voiced similar concerns. Again, due to time limitations, the lengthy approval process, and additional physician permissions and coordination required, this strategy was not realized.

### **Strategies to Reduce Barriers to Participation**

Over the course of the 12 month recruitment period, changes to the study design were also made in an attempt to encourage participation by decreasing possible barriers to participation. These changes were made in response to reasons given by potential participants for declining to participate as well as barriers we hypothesized in the intervention design. First, the study was changed from a randomized control trial to a quasi-experimental design in which the first 10 couples would be assigned to the intervention group and then, assuming recruitment went well for the intervention group, the following 10 couples would be assigned to a waitlist

comparison group, receiving education only. We hoped that being able to assure the first 10 couples that they would be assigned to the intervention group would encourage participation. Second, the eligibility criteria were expanded on three occasions to include: permanent ileostomies, temporary ostomies, and patients diagnosed with bladder cancer and living with a urostomy (temporary or permanent). The suggestion of including bladder cancer patients was recommended by the ostomy nurse, who indicated these patients also struggled significantly with sexual health. These changes in eligibility allowed us to accept the first couple, as they were uncertain whether the patient's ileostomy would be permanent. There was no interest from bladder cancer patients and no referrals of bladder cancer patients received. Last, an incentive (a \$100 online Amazon gift card) was offered to couples in recognition of their time commitment for participating; this did not result in any new accruals. Each of these changes to the design required REB amendments, changes to the flyer and online postings, updates to staff about expanded eligibility criteria for referrals, and outreach to other organizations (e.g., Bladder Cancer Canada) and departments within the hospital (i.e., genitourinary cancer clinic).

## **Potential Barriers to Recruitment**

### ***Barriers in Study Design***

The study design itself may have deterred couples from participating. Time, as identified by one of the patients in Study 2 (presented in Chapter 3), may have been a perceived barrier to recruitment. Couples were informed during recruitment of the study procedures included the completion of baseline, post-, and follow-up measures as well as the dyadic interview. These additional research commitments beyond completing the intervention itself may have been perceived as too great of a burden, especially as couples are adjusting to life after active treatment (e.g., returning to work). Moreover, results from the case-analysis of the intervention

suggest that some couples may have been confused as to the purpose of the pilot trial research and the fact that an intervention was being offered as part of participation, despite a thorough informed consent process. Notably, however, the one known instance of this did not dissuade the couple from participating. As suggested in Study 2, the ‘marketing’ of the intervention to patients during recruitment may benefit from giving a name to the intervention protocol. In addition, when the study included randomization, potential participants may have been hesitant to commit to participate given the uncertainty of group assignment and potential to have to wait to receive the intervention. Even with the change to a quasi-experimental design, and the expressed guarantee by the coordinator that couples would be assigned to the intervention group, this did not seem to make a difference on recruitment.

The process of screening couples was multi-step, presenting several opportunities for loss of contact with couples. Since the process typically began with an initial conversation with one member of the dyad, this partner often wanted to speak with their spouse prior to proceeding with screening. In some cases the couple was lost at this stage of recruitment – they either failed to return phone calls or the partner declined to participate without ever having spoken to the coordinator. In other cases, the partner who initially made contact with the coordinator would proceed with screening but their partner would avoid attempts of contact from the coordination so that screening could not be completed. Of the couples who were contacted by the study coordinator, four were lost during the screening process. A more streamlined screening process that included both members of the dyad together and did not depend on phone contacts may have facilitated recruitment.

Lastly, limiting the site to one hospital limited recruitment. Conducting a multi-site trial with coordination and cooperation with medical staff from across the province would likely have

increased patient referrals. However, this type of design was beyond the scope possible for the dissertation. Future attempts at the original purpose of Study 2 would likely benefit from a larger research team located at several different hospitals and the completion of the centralized REB (e.g., Ontario Cancer Research Ethics Board) as opposed to a hospital-specific REB to streamline the process. The ability to integrate the researchers within the appropriate clinic setting at each hospital would likely also benefit recruitment.

### ***Barriers in Intervention Design***

The way in which the intervention was designed may have also added barriers to recruitment. The couples-based intervention required participation from both patients and partners. Designing the intervention for couples was a deliberate choice in response to recommendations by Cancer Care Ontario based upon research evidence demonstrating increased efficacy when both members of the couple were present. However, the intervention was designed in such a way that individuals could not participate on their own should their counterpart not be willing to participate or if they were not currently in a relationship. Among the participants who spoke to the study coordinator about the study, five declined to proceed with screening or to participate because they either knew that their partner would be unwilling to participate or because their partner refused to participate. One individual was ineligible because he was single at the time. Of these, five of the individuals, including the single man, indicated that they would have participated alone if this had been an option. The difficulties in recruiting couples for interventional research in cancer is not uncommon (Heckel et al., 2018), with partner refusal being a common reason cited by women who refused a coupled-based psychosexual intervention after breast cancer (Reese et al., 2018). This suggests that re-designing the intervention so that it is adaptable in its application to couples, one member of a dyad, or a single



person would likely encourage greater program uptake, such adaptability had been recommended by other researchers who have encountered similar difficulties (Reese et al., 2018).

The intervention was also designed for a specific subset of patients; individuals diagnosed with CRC and living with a permanent colostomy. As previously described, this inclusion criteria was slowly expanded to include ileostomies, temporary colostomies and ileostomies, and then bladder cancer patients with urostomies (temporary or permanent) in the hopes of encouraging participation. Again, the choice to limit the patient population to those living with ostomies due to cancer was intentional given the additional documented challenges faced by these patients (Cotrim & Pereira, 2008; Reese et al., 2014; Sun et al., 2016). However, this inclusion criteria of course limited the recruitment and excluded bladder and CRC patients who did not have an ostomy, as well as individuals living with ostomies due to other reasons.

Lastly, the way the intervention was described, particularly in the study flyer, may have deterred couples from participating. The flyer included words like “sex” and “intimacy” to describe the topic of the intervention. During a consultation meeting with an expert researcher in the field of interventional sex research in oncology, it was suggested that such terms can be read as invasive or intimidating and that perhaps presenting the intervention as targeting body image in the flyers would have attracted more couples (A. Matthews, Personal Communication, February 8, 2019). Then, he suggested that once couples were more comfortable, the topic of intimacy and sexuality might be broached. Unfortunately, given time of the consultation, this advice could not be heeded for Study 2; however, it may be taken into account in future development. Similar changes to language used in the flyer may have included using terms such as ‘program’ as opposed to ‘treatment’ or ‘therapy’ – or in the case of the current flyer ‘intervention’ – as was done by Fredman et al. (2009) in their recruitment strategy for a couples-

based intervention following breast cancer in order to “minimize the risk of pathologizing or alienating prospective participants, particularly those who were not experiencing current relationship distress” (p. 669). In this spirit, future attempts at recruiting for the current intervention may benefit from consultation with patients and partners for which the intervention is designed in order to solicit their feedback on the quality of the flyer (e.g., ease of understanding, visual appeal, content, language). Such ‘market research’ of the flyer would be intended to increase self-referrals to the study, which were low.

### ***Systemic Barriers in Hospital***

Despite extensive efforts to reach out to HCPs within and outside of the hospital, few referrals were received. There is much research to suggest that sexual health is generally ignored by medical professionals working in oncology, despite evidence that patients would like to have regular and ongoing conversations with their healthcare team about this sensitive concern (Traa et al., 2014). A number of barriers to discussing sexual health with patients have been identified by physicians and front-line medical staff, including: time, lack of private space in the clinic, discomfort with discussing sex or intimacy due to fear of offending the patient, and a lack of training in sexual health and knowledge of how to address patients’ concerns (Fitch et al., 2013; Traa et al., 2014). An investigation into female patient’s refusals to participate in a study on a psychosexual intervention for rectal and anal cancers suggested that when medical staff were able to mention the study to patients prior to being approached by the researcher and when they were approached in a private space in the clinic, they were more open to consider the offer (Jennings et al., 2014). As it turned out, our host hospital required that a member of the patient’s circle of care approach them first, so we were in a way dependent on HCPs having these conversations. Unfortunately, when referrals did come from HCPs, some patients were still in

active treatment and so ineligible for the study, suggesting a possible issue with the timing of the approaches.

### **Rationale for Study 3**

Given the difficulty in reaching the target audience of the intervention, there was a need to better understand some of the barriers to recruitment. An intervention is not useful if patients are not interested, willing, or able to engage in it. Moreover, an intervention will not be used, if its target audience is not made aware of its existence as a resource at their disposal. While owning the potential barriers to recruitment inherent in the study design and intervention itself, we began to wonder whether the patients for whom the intervention was designed were particularly difficult to engage in research about a sexual intervention, having both a cancer diagnosis and ostomy, compared to other cancer patients without ostomies or individuals living with ostomies not due to cancer. In other words, we questioned whether having an ostomy, in and of itself, presented its own unique barrier. We also wondered how systemic barriers, as previously identified in the literature, were at work within the host hospital and how these may have impacted patient recruitment through referrals. For this reason, a third study was undertaken. The purpose of the study was to better understand barriers to recruiting this patient population by capitalizing on the insights of HCPs who work with them on a regular basis and so could draw upon their professional training and clinical experience within the hospital setting to identify potential systemic and patient-specific obstacles to recruitment. This information is key to improving the acceptability and feasibility of the intervention and its integration within the host hospital.

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## Chapter 5

### **Study 3, Couples' Non-Participation in a Trial of an Internet-Delivered Intervention for Intimate Re-Adjustment to an Ostomy After Cancer: Health Care Providers' Perspectives**

Sexual health is largely ignored in cancer care, despite patients' endorsement of both functional and psychosocial difficulties related to sex and sexuality during and after treatment (Averyt & Nishimoto, 2014; Fitch et al., 2013b; McLeod & Hamilton, 2013). Time, privacy concerns, discomfort, and a lack of expertise are commonly cited reasons by health care providers (HCPs) for overlooking sex in cancer treatment (Averyt & Nishimoto, 2014; Fitch et al., 2013b; McLeod & Hamilton, 2013; Traa et al., 2014). Recently, Cancer Care Ontario (CCO) published guidelines for addressing sexual health in oncology that emphasize the importance of supporting the sexual well-being of all patients (Barbera et al., 2016). Regrettably, available literature highlights the paucity of research on interventional approaches to addressing these concerns, especially among couples coping with cancers other than breast and prostate (Badr & Krebs, 2013; Gilbert et al., 2009; Jonsdottir et al., 2018; Regan et al., 2012). As such, it is increasingly important that efforts are dedicated to developing sexual health interventions for cancer patients, especially for disease-sites that are relatively understudied, and evaluating their efficacy through interventional trials. Unfortunately, recruitment for psychosocial interventional trials for cancer patients and survivors can be challenging (Stanton et al., 2013) and may be further complicated when the target of the intervention is an aspect of care as sensitive as sexual health (Jennings et al., 2014; Reese et al., 2018; Shaffer et al., 2018). Moreover, while the CCO guidelines and available literature on sexual health interventions in oncology recommend the inclusion of intimate partners (Barbera et al., 2016), recruiting dyads for couple-based

interventions compounds these challenges (Fredman et al., 2009; Heckel et al., 2018; Reese et al., 2018).

The present study examines one example of a novel psychosexual health intervention developed for couples affected by either colorectal cancer (CRC) or bladder cancer (BC) and a trial of the intervention that was, unfortunately, underwhelmingly successful in its recruitment efforts. Through interviews with HCPs, the present study seeks to identify potential reasons for couples' lack of uptake of the intervention. In turn, the identification of barriers to recruitment may inform the future development of psychosexual interventions for patients diagnosed with cancer, particularly CRC and BC, and the design of their clinical trials.

### **Background to the Present Study: A Trial of a Novel Psychosexual Intervention**

CRC and BC survivors report changes to sexual health as a significant obstacle in their recovery, and these challenges are compounded when patients are living with an ostomy (Cotrim & Pereira, 2008; Sun et al., 2016; Traa et al., 2012). Unfortunately, as highlighted in the OCC guidelines, few studies have attempted to address the needs of these patients. In an effort to address this gap in the literature, we developed an intervention targeted toward these patients.

The intervention consisted of two 1.5-hour sessions with couples delivered via a secure and no-cost Internet-based videoconferencing software. The purpose of the sessions was to provide patients living with an ostomy after CRC and/or BC, and their intimate partners, with the opportunity to have facilitated conversations about the sexual and intimate changes they have experienced as a result of the cancer and its treatments. The intervention adopted a resilience-oriented approach in that the structure of the sessions was designed to assist couples in identifying dyadic strengths to enhance their sense of self-efficacy in coping with these changes. The intervention also emphasized enhancement of intimacy through the use of well-established

sexual counselling exercises, specifically sensate focusing (Masters & Johnson, 1970), and research in sexual adjustment after prostate cancer, specifically a value sharing exercise based on the Physical Pleasure-Relational Intimacy Model of Sexual Motivation (PRISM) (Beck & Robinson, 2015; Hampton et al., 2013).

Recruitment efforts consisted of self-referrals and health care provider (HCP) referrals to the study coordinator. Participation was open to couples over the age of 18 years and of any sexual orientation and gender-identity. Couples who endorsed changes in the sexual and/or intimate relationship related to the patients' cancer treatments and/or ostomy were encouraged to participate. To be eligible, patients also had to be at least 3-months post-active treatment. Advertisements for the study were posted within the hospital clinic and waiting areas, shared online and in-person through community-based cancer and ostomy organizations, and posted in online communities dedicated to ostomy patients. Patients and partners were directed to contact the study coordinator if they were interested in participating. HCPs across disciplines, including surgical oncologists, radiologists, nurses, wound ostomy continence (WOC) nurses, psychosocial oncology clinicians, were also solicited to share the study advertisement with appropriate patients and, with the patient's consent, provide their name to the study coordinator for follow-up. Extensive efforts were taken to inform HCPs of this opportunity, including presenting at hospital rounds and educational conferences; emailing study advertisements to all HCPs working in relevant hospital departments and clinics in southern Ontario; sharing the study advertisement with relevant professional list-serves; contributing an article to the hospital intranet blog *Your Health Matters* about the project; and approaching HCP individually to solicit their support in referring patients to the study.



Originally, participation was only open to patients diagnosed with CRC who were living with a permanent ostomy and their partners. In an effort to enhance recruitment, inclusion criteria were later amended to expand their breadth from originally requiring patients to have been diagnosed with CRC and living with a permanent colostomy, to the inclusion of patients with CRC living with either a temporary or permanent ileostomy or colostomy, to the inclusion of BC patients with either a temporary or permanent urostomy. The trial was also changed from a randomized control trial, with an educational-control group, to a quasi-experimental design in which the first 10 couples were planned for assignment to the intervention group and the subsequent 10 couples planned for assignment to an educational-comparison group. The reasoning behind this design change was that a guarantee of immediate access to the intervention, as opposed to random assignment with the possibility of a 3-month wait, might enhance the first 10 couples' motivation to participate. Ultimately, none of these changes led to additional recruitment.

A total of 3 patients self-referred to the study, each reporting that they had learned of the study from advertisements shared in online forums and ostomy organizations, and 19 patients were referred through HCPs, specifically a surgical oncologist ( $n = 2$ ), a WOC nurse ( $n = 14$ ), radiation therapist ( $n = 1$ ), a registered practical nurse ( $n = 1$ ), and a urologist and nurse team who worked at another hospital ( $n = 1$ ). In addition, six patients who had participated in previous research with the study team and had provided permission to be contacted about future opportunities for participation, were contacted. Of the 28 prospective patients and/or partners, 32% ( $n = 9$ ) were deemed ineligible (e.g, in active treatment, residing outside of Ontario, not in a relationship, patient deceased) upon screening with the study coordinator. Of the 19 remaining prospective participants, 17 couples (90%) declined and two couples (10%) consented to

participate and completed the interventional trial. The reasons for declining participation among the other 17 prospective participants included: partner unwilling to participate (16%,  $n = 3$ ), sex not a priority in the relationship (16%,  $n = 3$ ), doing well sexually (21%,  $n = 4$ ), currently receiving medical intervention for sexual dysfunction and satisfied with focusing on that treatment for the moment (5%,  $n = 1$ ). An additional 10% ( $n = 2$ ) did not provide a reason for declining, and 21% ( $n = 4$ ) did not respond to attempts at contact. Of the two couples who completed the intervention, one did so in-person instead of via the Internet-based videoconferencing software due to concerns about confidentiality of the online environment.

### **Current Study**

In response to the low interest and enrollment in the interventional trial (despite extensive recruitment efforts over the course of 12 months), a second study was undertaken as a corollary to the original study. The purpose of the present study was to better understand systemic and patient-related barriers to recruitment from the perspective of HCPs who work clinically with the target population. Given the low number of referrals to the study, we were interested in investigating the reasons for patient reluctance to engage in research about a sexual intervention; in other words, we were interested in understanding patient-factors that might impact their willingness to take part in a psychosexual interventional research trial. Given the conundrum concerning low recruitment, a decision was made to pose this question to HCPs rather than patients themselves. We also wondered if and how systemic barriers to addressing sexual health in oncology, as previously identified in the literature, were at work within the host hospital and how these may have impacted patient recruitment. This study capitalized on the insights of HCPs who work with the target population on a regular basis and could draw upon their professional expertise and clinical experience within the hospital setting to identify potential systemic and

patient-related obstacles to recruitment. As emerging health policies and guidelines highlight the need to address sexual health in cancer care, a clearer, empirically based understanding of barriers to engagement in research of interventions targeting sexual health is vital to the advancement of care in this area. Given this area is largely ignored in current practice, the results of this study may also inform our understanding of the clinical acceptability and feasibility of psychosexual health interventions in cancer and their integration within a hospital setting.

## **Method**

### **Design**

A qualitative thematic analysis of interviews with hospital-based HCP who treat patients with ostomies after CRC and/or BC was undertaken to understand potential barriers to recruiting couples for a trial of an Internet-delivered intervention for sexual and intimate re-adjustment. The study draws upon the clinical experiences and professionally-informed observations of HCPs across disciplines to identify both systemic barriers and patient-related barriers to recruitment with this specific patient population.

### **Recruitment**

HCPs were mainly recruited via direct approach, either in-person or email, by the study coordinator/facilitator and clinical supervisor. An effort was made to identify and approach HCPs from diverse disciplines who work directly with patients diagnosed with either BC or CRC and living with an ostomy. HCPs who had provided patient referrals for the interventional trial, had expressed interest in the intervention when learning of it, and/or were known to have training and clinical interests in sexual health were also approached individually. Additionally, seven physicians including urologists, surgeons, and radiation and medical oncologists working in the cancer centre were approached directly, but only two agreed to participate. An informational

flyer about the study was also emailed to list-serves of departments treating bladder and colorectal cancer on the study's behalf by the manager of the Patient and Family Support program and the nurse manager of the gastrointestinal and genitourinary departments. Interested healthcare providers were directed to contact the study facilitator/coordinator. Other strategies to reach a wider audience of HCPs included a post on the hospital's intranet blog about the research. There were no HCPs who self-referred to the study.

### **Interview**

All HCPs completed a 30-60 minute semi-structured interview (see Appendix G for interview protocol). Open ended questions were used to encourage HCPs sharing and elaboration. First, HCPs were asked questions about their experiences and perspectives in addressing sexual health in their practice, particularly with patients that have ostomies due to CRC or BC. Second, HCPs were asked to share their perspectives about potential barriers to recruitment for the aforementioned study, given their clinical experience with the target patient population in the hospital system. Experiences and impressions shared by HCPs in early interviews also informed lines of questioning in later interviews, such that ideas about barriers identified by early interviewees could be presented to later interviewees to reflect upon in light of their own experience. The study coordinator/facilitator conducted all but one interview, which was conducted by another research assistant.

### **Analysis**

A theoretical thematic analysis was conducted to better understand systemic and patient-related barriers to recruitment. Audio-recordings of interviews with HCPs were transcribed verbatim. N-vivo for Mac Version 12 software was used to manage and organize the qualitative data. Interviews were first read in their entirety to gain an overall appreciation for HCPs'

perspectives. Then each interview was read again and divided into ‘meaning units’; a block of text (e.g., a few words or several sentences) that convey a single concept or idea (Giorgi, 1970). Meaning units were then initially coded for semantic meaning related to barriers to enrolment. Next, codes were grouped by meaning to form themes; themes were reviewed and refined to ensure they captured the meaning intended by the code label, and then, that formed an accurate representation of the whole data set (Braun & Clarke, 2006). Finally, themes were organized into a thematic map representing the relationships between them (Braun & Clarke, 2006).

The current analysis assumed that the low enrollment in the trial of the psychosexual intervention was impacted by barriers at two ‘levels’ of engagement: (1) at the level of engagement in a research trial and (2) at the level of engagement in a sexual health intervention. In other words, it was assumed that barriers were present that were impacting patients and/or partners’ willingness to participate in a research trial and that barriers were also present to deter patients and/or partners’ from participating in the intervention. The barriers could be unique to one level of engagement or could be operating across levels. This assumption was made because the intervention was carried out within the context of the trial, and as a consequence, the recruitment for the trial and engagement with intervention were inextricably tied within the current analysis.

In an inductive approach to analysis, the interview texts were coded to identify themes related to barriers to recruitment. While we remained open to identifying any kind of barriers, we held assumptions about some of the barriers that may be identified within the HCP transcripts. We anticipated that HCPs would describe patient-related factors to declining participation, systemic barriers that influence referrals to the study, and obstacles related to the intervention and trial design. We theorized that, in light of the few self-referrals and HCP

referrals to the study, this patient population (and their partners) may be particularly difficult to engage in psychosexual interventional research due to patient-specific factors (e.g., characteristics of their disease and rehabilitation trajectory), as well as systemic barriers within the hospital that reduce the likelihood that HCPs will have conversations with their patients about sexual health and, in turn, refer them to sexual health interventions such as the interventional trial in question. We also remained open to the notion that the intervention, either by its very nature as a sexual health intervention or by way of its design and subsequent implementation within the context of the trial, could have raised other obstacles to patient engagement. These predictions were informed by a growing body of literature reporting barriers to addressing sexual health in oncology care, specifically literature suggesting that HCPs rarely initiate conversations about sexual health with their patients for a myriad of reasons, and the disparity of problems in degree of sexual re-adjustment between patients with and without ostomies after CRC and BC.

We maintained a critical realist ontology in relation to the text data (see Weed, 2009). From this stance, we assumed the existence of real barriers to recruitment and a direct relationship between interviewees' meanings and their use of language to describe their experiences, while also recognizing that each HCP will only be able to describe barriers to recruitment from their own perspective (Weed, 2009; Willig, 2012). Additionally, within this stratified ontology is a belief that the phenomena (i.e., the barriers to recruitment) cannot be directly measured, and thus there is an interaction between the researcher and the phenomena under investigation through interpretation, which is consistent with an interpretivist epistemology (Sandelowski, 2000; Weed, 2009; Willig, 2012). In keeping with this stratified critical realist ontology, themes were coded at a semantic level to gain a rich description of

themes across the data set and then interpreted in relation to relevant existing literature (Braun & Clarke, 2006). The lead analyst (first author) was the co-developer of the intervention, study coordinator and facilitator of the interventional trial, and interviewed all but one of the HCPs. In an effort to maintain reflexivity during analysis, memos to track interpretation of codes and organization of themes were made throughout the process.

### **Researcher Positioning**

Within the current study, a comment is warranted on the first author's role within the research, her relationship to the host institution, and her broader social positioning. The first author was the co-developer of the intervention, acted as the facilitator of the intervention, and was the coordinator of the study, and thus responsible for recruitment initiatives. Moreover, she led the analysis within the current investigation of barriers to recruitment. The first author is also a graduate trainee in clinical psychology at a local university and her research supervisor is cross-appointed at the host hospital. As such, the first author was not integrated within the hospital system, unlike the healthcare providers interviewed within the current investigation. Finally, the first author is a young, Caucasian/white, heterosexual, and cisgender woman; it is important to acknowledge that these broader social identities and subjectivities may have impacted couple-recruitment (e.g., patient discomfort speaking with a woman about sex) and, in keeping with the stratified critical realism ontology of the analysis, would have impacted her semantic description of the themes as at least some degree of interpretation is necessary (Sandelowski, 2000).

### **Participants**

A total of 11 HCPs consented to participate in an interview. One HCP, a social worker, was employed at another hospital in Ontario; all other HCP were located at the host hospital for

the trial. Participants were from a range of disciplines and included: a medical oncologist ( $n = 1$ ), a surgical oncologist ( $n = 1$ ), registered practical nurses ( $n = 2$ ), wound, ostomy, continence nurses ( $n = 3$ ), a radiation therapist ( $n = 1$ ), social workers ( $n = 2$ ), and a psychological associate ( $n = 1$ ). On average, participants reported an average of 21 years ( $SD = 8.42$ , range = 8-35) of experience in their discipline and all participants worked directly with CRC or BC patients, or both. Six of the HCPs indicated that they had at least some training in sexual health (e.g., half-day seminar at hospital, graduate level coursework).

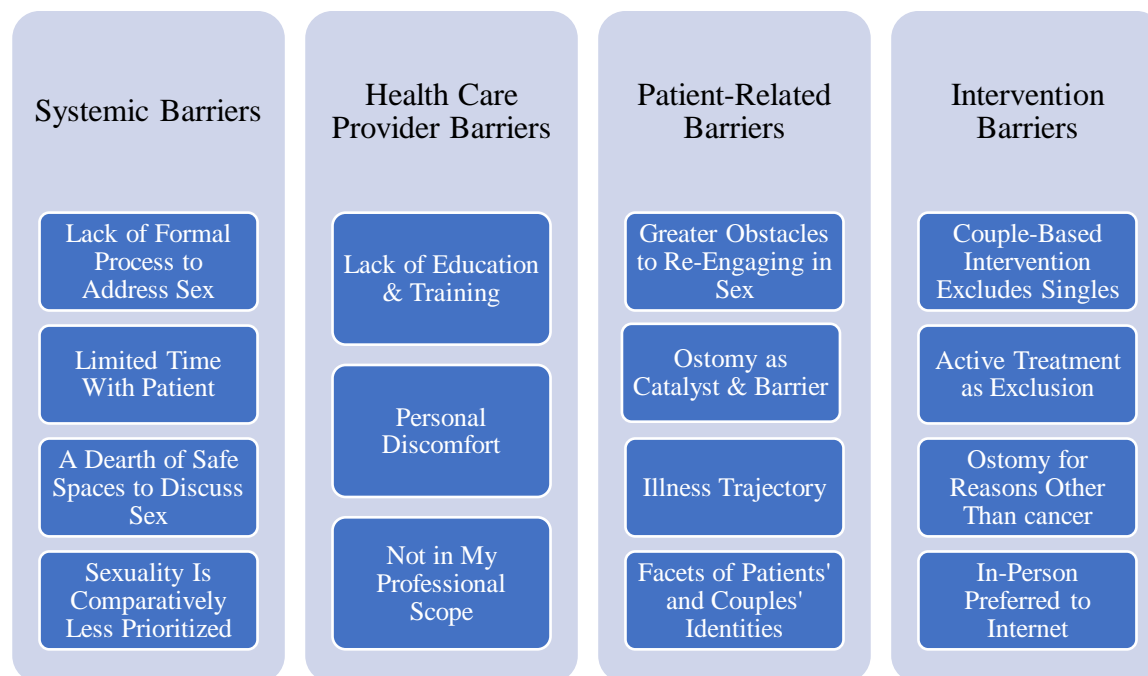
## **Results**

The thematic analysis of interviews with HCPs resulted in the elucidation of the following categories of barriers to recruitment: (1) systemic barriers, (2) health care provider barriers, (3) patient-related barriers and (4) interventional design barriers. Subcategories associated with each theme are presented below in italics. See Figure 4 for an illustrative representation of the major categories and subcategories of the thematic analysis.



**Figure 4**

*Barriers to Recruiting Couples in a Trial of a Psychosexual Intervention After Ostomy Surgery for Cancer*



### Systemic Barriers

Systemic barriers referred to obstacles to recruitment related to the overall culture and standards of practice within the hospital setting. Almost all HCPs spoke about a *lack of formal processes* within the cancer centre to assess patients' sexual health needs, identify patients who are struggling or experiencing distress related to sexual health, and to connect these patients with appropriate sexual health support resources. As a front-line nurse described the situation, "Even just knowing where to refer — like for me, as a nurse, I want to be able to give some concrete suggestions or help, like advise them on what to do, but if I don't know what's available, then I'm less inclined to really ask them about it." HCPs identified that parameters of health-related quality of life such as pain, depression, and fatigue, are standardly assessed at each visit via self-report measures (e.g., the widely used Edmonton Symptom Assessment System or ESAS), which

in turn cues them to initiate conversations with their patients about these topics. Sexual health, however, is not among those aspects of well-being screened for at the hospital with patients being treated for BC or CRC. This failure within the system to formally integrate assessment of sexual health within standard care left the onus on HCPs to develop their own practices for addressing sexual health – or not. As HCPs described, some took a matter-of-fact approach in raising the topic as a regular part of their assessment process with all patients (an approach that was adopted primarily by HCPs with training in sexual health), while others described initiating conversations about sex on a case-by-case basis or indirectly by raising issues of fertility, the impact of the ostomy on body image, and cancer’s effect on relationships in general. Still others reported that they did not raise the issue themselves but chose to “follow the patient’s lead” in talking about sex, largely out of concern for offending the patient (e.g., sex considered taboo, perceived cultural or religious opposition to discussing sex) or risking the patient-provider relationship (e.g., perception of over-stepping their role). Thus, if patients did not directly verbalize or give “clues” that they were concerned about sex, the HCP would assume that sex was not of concern to the patient. A lack of coordinated sexual health care and referral process meant physicians working with the same patient did not know if their colleagues would be raising this issue with their shared patient.

HCPs spoke also about *limited time with the patient* as an overarching systemic barrier to addressing sexual health with their patients. Among nursing, a team-based approach to staffing meant “we don’t know where we’re going to be every day. We could be in clinic, we could be on the phones, we may not be in that clinic again, we may not see that patient again for a year.” According to this nurse, limited previous encounters with the patient and little time for chart review meant she may not even know the patient had a stoma. Additionally, front-line and

wound and ostomy nursing staff discussed the need to prioritize and triage patient concerns during the short time they had at each visit given the high volume of patients they see, with less importance typically placed on sexual health compared with more immediate issues like wound management or pain. One physician described being with patients “5 minutes at most” during a typical clinic day.

Sexual health conversations necessitated a second meeting, but one that might not necessarily happen. When contrasting the sexual health needs of CRC and BC patients with ostomies against the sexual health needs of patients from other cancer site groups, HCPs held the perception that the sexual difficulties faced by CRC and BC patients were more complex as the cancer treatment did not necessarily impact function of sex or sexualized organs, and thus required more time to understand and address. HCPs across disciplines also identified that speaking of a sensitive subject such as sex benefited from a long-term relationship with patients and on-going conversations to assess sexual health needs as these may vary in priority for the patient over the course of treatment and recovery. Notably HCPs admitted that without a history of working with the patient they would be unlikely to “risk” raising the issue of sex themselves. As a front-line nurse interviewed described, this could have impacted patients’ responses to the idea of participating in the study intervention and even the likelihood that a HCP would inform the patient of the opportunity:

...it’s almost like the culture—like, we’re not asking it at any point really, how their sexual health is, so then when all of a sudden we ask them if they want to participate in a study, you know, that may be a lot for someone to take in. And they may not feel comfortable discussing it with someone they may not know.

A social worker expanded on this idea, theorizing that it could have proved advantageous to the study’s recruitment to have been able to capitalize on the patient-HCP relationship that develops over time, if a system were in place to identify the HCP with the strongest rapport:

In our cancer centre, there's no such thing as like rounds anymore, we don't, you know, talk about patients and consult together and work together, so... but, you know, it'd be interesting to—if you could identify someone on the team that that patient has a good rapport with, and that would be the person who would talk about the intervention, you know. If that would help. Right? So, somebody that they have a really good rapport with, if they were to say, you know, 'I want to tell you about this program, and I know this is sometimes hard to talk about, but I'm wondering if...blah blah blah blah.'

HCPs held differing perspectives about the optimal timing of making referrals to the intervention. Some posited that raising the issue early in treatment, even if sexual health was not currently of concern to the patient, was beneficial in normalizing these concerns and re-assuring patients that a resource existed for them to access following treatment. Others felt that raising the issue of sex, and the study trial, was inappropriate early in treatment (e.g., pre-operatively) as from their experience patients were focused on survival and immediate physical and practical complications of treatment. While the intervention was designed to be delivered to couples following the patient's active treatment, HCPs indicated that they may only have contact with patients prior to or during treatment and not at follow-up, meaning that there could be a significant lag between informing patients of the study and the time when they became eligible to participate, which may engender frustration for patients and/or result in a loss of participants who forgot about the study post-active treatment. Moreover, two of the WOC nurses highlighted that a lack of automated system to track a patient's progress through treatment meant that contacting patients once they were eligible to participate (e.g., 1-month post-treatment) required additional administrative time that they did not have available in addition to their clinical responsibilities. As a result, HCPs suggested that recruiting patients through community care organizations (e.g., CCAC) or family physicians in the remission period may prove more successful as patients would be completed their active treatment and more likely to be progressed in their adjustment experience. An oncologist extended this point by arguing that someone

outside of the patients' long-term oncology care team should present the interventional trial to patients, reasoning that patients could feel a pressure to participate if he were to inform them of the trial because of their necessarily long-term relationship. As he explained it:

...if I try to put myself in someone else's shoes, I would be much less comfortable talking about anything about my sexuality or intimacy with someone that I know that I'm going to see long-term and have multiple follow-up visits [with] Whereas, if it was a completely different channel that I could turn on and off. Like, 'I can't end this relationship, right?' With me. That's a relationship, like, 'He's going to have to know, if I want my cancer looked after long-term, and I want to be followed long-term, I need to play along with this guy.' '[I've] got to answer his questions, but like we have to get along and we...' Whereas, 'You know, [research coordinator], I'm kind of getting uncomfortable with this entire thing. I'd rather not be involved.' They never see you again, end of story.

In this way, the seemingly advantageous long-term relationship that we had hoped to capitalize upon served as an ethical barrier to this clinician's comfort and willingness to inform patients of the study. Physicians interviewed offered guidance for breaking down some of the systemic barriers related to time. They recommended that the study co-ordinator be present in the busy clinic setting to remind physicians about recruitment and the eligibility criteria as well as to represent an individual that is not involved in the long-term medical care of the patients and who, following an introduction by the physician, could be available to spend time reviewing the study details with patients. They also recommended that individual face-to-face meetings between the study team and physicians about the intervention and its trial would help physicians to keep the opportunity top of mind when meeting with their patients.

HCPs also identified *a dearth of safe places to discuss sex* in the hospital. Namely, they identified that they were sensitive to the idea that such personal matters might be overheard in busy clinics with limited appropriate physical places for holding private conversations. Without privacy, HCPs opted not to initiate such conversations, deeming them inappropriate to the

setting. Moreover, one HCP identified that messaging in the CRC and BC clinics did not communicate to patients that the cancer centre was a space in which sexual health concerns were of priority, let alone an appropriate venue to address such concerns. This HCP contrasted the messaging of sexual health within breast and prostate cancer clinics and the relative impact on patients' expectations of care:

You walk down the radiation hall, or in prostate clinics, and you see the guides, [or] you see “prostate cancer: sexual health”, “prostate cancer: erectile dysfunction”, “prostate cancer: hormonal changes”. You don’t see that in the bladder cancer clinic... So if I was a man walking down [the hall] and saw those things, I would know it’s a safe space, it’s an engaged space, it’s a knowledgeable space, right? Whereas you walk down [to] the bladder cancer [clinic and] you don’t see anything on sexual health. So I think messaging and imaging and things like that can really help create a safe space for patients... It kind of lets them know that they can raise that topic... and that there’s interest, and support, and expertise that can address those concerns, right?

The disparity in messaging within the physical spaces of the clinics alludes to another systemic barrier to addressing sexual health within BC and CRC, specifically that from HCPs' perspectives *sexuality is comparatively less prioritized*, receiving relatively less attention in CRC and BC compared to other cancer sites. Several HCPs identified that in comparison to cancers that more “obviously” relate to sexual organs, such as breast, gynaecological and prostate cancers, sex is “not routinely addressed” in CRC or BC. The radiation therapist reasoned that that the disparity exists “... because you know the actual anatomy that—where they have cancer—it’s not as obvious to people that there are going to be other organs or structures that are going to be affected,” a point that was echoed by a social worker who explained, “when you think of prostate function, penile function, testicular function, you think of sexual health, but you don’t—like, a lot of people’s minds don’t go directly to sexual health when they think of bladder. They think of voiding. So we, yeah, it doesn’t have the same spotlight.” HCPs also described the healthcare system as “siloes” by disease site, with distinct boundaries between areas of practice

and limited communication, which further compounded the problem in addressing sexual health in CRC and BC. One HCP recalled a patient who had been treated for CRC cancer and presented to a sexual health clinic following painful sex:

She said that she'd gone to her doctor multiple times and she'd explained to them that you know whenever she tried to have sex it was painful and the doctor kept saying to her, 'Well, that's not anything to do with me. That's gynecological.' You know, 'Your cancer was like the GI site—that is what I do.'... So it's like, 'Oh, your vagina's got nothing to do with me...I don't know about *that* part. I know about, you know, *this* part.'

Given this low prioritization of sexual health in CRC and BC care, HCPs explained that there is a lack of sexual health education information targeted toward these disease sites, and thus little awareness among these patients that sexual issues are common throughout their disease trajectory. Relative to other site-groups, patients with CRC and BC are denied the normalization function that clinic signage and educational materials about site-specific sexual concerns would otherwise provide. As such, HCPs explained, "you can't go into the conversation sort of presuming as much [about the patient's knowledge], I think, as with the other sites." Similarly, HCPs lamented that there were few clinics, if any, to which they could refer these patients in a timely manner. HCPs across disciplines agreed that the combination of lack of awareness and resources served as significant barriers to addressing sexual health:

... there is a lack of services for people. So when there is a lack of services and a lack of resources, then you, you know, you do hesitate to bring up the topic. Because it almost seems cruel, you know. Like, sort of bringing the topic up and putting it out there with the patient, and then just saying, 'Okay, well, I hope something happens for you.' You know? 'Have a nice day!' [chuckles]. You know, you have to be able to offer people something.

While the interventional study was designed to begin to address this gap in resources for this specialized patient group, only one HCP – a wound nurse – directly identified the availability of

the study as a resource she felt she could offer in cases when she raised the topic of sexual health with patients.

### **Health Care Provider Barriers**

Barriers to recruitment specific to HCPs were also identified through the thematic analysis; these were distinct from systemic barriers in that they related to recruitment obstacles at the level of the individual or discipline of the HCP. Specifically, HCPs identified several barriers in their abilities and comfort as professionals to address sexual health. As one social worker with training in sexual health explained, when recruiting couples “[you need] somebody who has that comfort level, who can explain, you know, what the benefits potentially could be, because I think part of what’s happening is—the barrier is—you know, the healthcare providers or system aren’t maybe talking about it, or feeling comfortable talking about it...” The most frequently identified barrier was a *lack of education and training* in addressing sexual health. Of the HCPs interviewed only six indicated that they had received adjunct, formal training in addressing issues of sexuality, but these varied significantly in their depth and scope. Those with minimal or no training described discomfort broaching the topic, an unawareness of the sexual health issues of their patients and the prevalence of these, uncertainty in how to answer patients’ questions about sex, and/or an unfamiliarity with sexual health interventions or resources to which they could refer their patients. The ability to relay information about sex clearly and in laymen’s terms to patients as well as ignorance with regard to how to sensitively address the particular issues of LGBTQ+ individuals and couples, especially that of gay males who may experience stigma related to contracting CRC or whose primary source of sexual pleasure was under threat, were identified by HCPs as particular areas of perceived incompetence. Others indicated that they were comfortable with initiating and negotiating medicalized conversations surrounding



sexual health but not psychosocial aspects of sexuality. For example, the surgical oncologist regularly had conversations about sexual health in the pre-operative consent process, but avoided discussion about the implication of physical challenges, in part because he did not have training in how to respond to such concerns:

I'm extremely comfortable talking about the medical components. I'm less comfortable talking about the psychosocial components... So, in terms of, you know, the conversation to tell a forty-something-year-old woman that you're going to need to remove her vagina, there's going to be a closed wound where your vagina used to be in order to save your life, that's a conversation I have... and I'm comfortable with that conversation, I'm comfortable with how traumatic that is—I'm comfortable with making sure there's three follow-up visits to make sure that she's in the right place before the operation... Afterwards, I'm very comfortable saying, like, 'I'm going to refer you to this person, I'm going to refer you to the [sexual health clinic] to deal with whatever,' but as far as, you know, 'How has your intimacy been with your partner since you have no vagina anymore?'—I don't ask.

Interestingly, some HCPs indicated that they would refer patients who were concerned about sexuality to the Patient and Family Support (PFS) program in the cancer centre, but one of the PFS clinicians stated that she too felt limited in her ability to address these issues from a psychosocial perspective due to constraints on time and expertise in addressing sexual concerns - often opting instead to refer patients to community-based psychologists with specializations in sexuality. Almost all HCPs indicated that additional opportunities to receive education in sexual health would help their confidence in raising the topic of sexuality with their patients. However, many HCPs complained that despite their desire to develop their competencies in sexual health, they had limited time in their schedules to seek education and clinical training. Fortunately, some HCPs referenced ways in which the hospital as an organization had been supportive in their learning about sexual health including paying for the cost of a course in sexual health and hosting departmental in-service training about sexual health. Those HCPs who had sought education in sexual health reported that they worked to educate their colleagues through informal

consultation and formal presentations. Some were known among their fellow HCPs as professionals who were comfortable in addressing such concerns, and thus were often called upon for clinical support when patients of untrained HCPs were experiencing sexual health concerns.

In addition to a lack of adequate education and training, HCPs also identified a *personal discomfort* in addressing sexual health, which could extend to discussions of the intervention with patients. HCPs suggested that personal – non-professional – factors may influence the degree of comfort they feel in discussing sex with their patients. One HCP disclosed her belief that having had sexual partners in her own personal life who encouraged her to be more open and expressive in her sexuality (in contrast to her “Catholic and relatively conservative” upbringing) increased her degree of comfort addressing sexual health in her professional practice by normalizing sexuality as a universal human experience. On the other hand, one WOC nurse suggested that she is much more comfortable discussing sex in her professional life than her personal life. While another participant stated that some HCPs are uncomfortable with sex across all aspects of their lives:

...some of my colleague have come to talk to me and say, ‘Look, I know this stuff’s important, but I can’t get involved in it’ or ‘I’m not the best person to do it.’... when I think about [those who aren’t comfortable], I think, well part of it may be to do with—I mean, it’s their upbringing or their religion or things like that – they just cannot. And some of my colleagues I remember one of them read something once in a patient’s record that someone had wrote about masturbation and they just said, ‘Oh no, no, no, no. No. No. No. I’m not going there.’

For some HCPs, being of a different gender than their patient increased their own embarrassment and discomfort about talking about sex or led to their perception that the patient would be uncomfortable, resulting in avoidance of the issue. HCPs also acknowledged that as a society – not only within healthcare – we do not openly discuss or teach about sex, as one social

worker stated, “I think it’s still taboo... most of us are having sex or are sexual in some way, but... most of us, I think, haven’t been socialized to be comfortable talking about [it].” This may be especially salient, as one participant pointed out, when working with gay men or other individuals who enjoy anal sex because HCPs may be “uncomfortable with people having sex in ways that they’re not familiar with.” HCPs expressed that written information about the study assisted in breaking through the discomfort:

...the [study] flyers that you had, I think we just presented it to them and said, ‘[Oh], we have this study going on at the moment, and it’s—you know, you would be eligible to participate. Would you be interested in something like that?’ And so, you know, really you don’t even need to mention the words sexual health or sex or anything like that if you don’t want to or you feel uncomfortable.

In some cases, HCPs indicated that having the study flyer at their disposal helped to initiate conversations around sexual health that they may not have necessarily had and led to addressing matters of sexual health within their clinical encounter.

For one HCP, there was a discomfort in broaching the topic of the intervention because of a belief that sexuality is *outside of his professional scope*. From his clinical experience, to raise the topic of sexuality – even within the context of informing patients and their partners about the intervention being offered – would be unwelcome because of his role in his particular speciality of health care. As he explained:

I don’t think I’ve ever had a patient come to me and engage me in any discussion around their sexuality. Or about their self-image, or about feeling attractive, or attracting others, or anything like that... Which is really kind of where the study lived. [When I did tell patients about the study] you could tell that, very quickly, because we weren’t talking about sexual function, because we were talking about sort of intimacy and connection [in] the setting of a stoma, people weren’t super receptive to it. Whereas when you talk about sexual function—Like, I’ve never had a patient where I said, ‘How’d your erection go?’ that they shy away from that question. They want to tell me. Because it’s all kind of part of the surgery, it’s part of what we talked about before and now I want to know how things are going... Part of the surgical aspect is I don’t—I’ve never had that relationship with this patient. So it almost is this weird dynamic where it’s like, ‘You don’t know me in that context. And you’ve never tried to know me in that context’, because I haven’t

and I've never asked and it's kind of none of my business which is weird for a doctor to say, like—but in fairness, it's not part of their—like we're not asking, like all that functional stuff is very much part of their colorectal cancer pathway. It's expected for you to ask those questions. It's expected; it'd be wrong if I didn't. [Whereas] the intimacy part, or the relationship part, [or] whatever, almost feels intrusive, like it's not something we've ever discussed before, it'd be really weird to tell you about this, like we don't have that connection....It's more like, 'I need you to be this sterile, like, surgeon-y guy'—I have good relationships with my patients, [and we] have great conversations and whatever, but, 'I need you to be, like, my cancer guy. Not my life guy, I can go get a life coach, I can get a—my family doctor can talk about, like, this type of stuff—but I need you to be my surgeon-person.'

While this barrier was uniquely identified by the surgical oncologist and not expressed by members of other disciplines interviewed, it suggests that surgical oncologists may not represent the most appropriate patient-provider relationship in which to recruit patients for research related to sexuality and intimacy. For this HCP, the patient's primary care provider was regarded as the most suitable individual to clinically address issues related to sexuality because of their emphasis on the holistic care of the patient.

### **Patient-Related Barriers**

Patient-related barriers to recruitment referred to clinical and demographic characteristics of the intervention's target population that may have contributed to their low enrollment in the interventional study. Patient-related barriers identified by HCPs included site-specific barriers unique to CRC and BC as well as patient barriers that could be potentially applicable to other cancer site groups or other individuals living with colostomies, ileostomies, and/or urostomies not due to cancer. HCPs almost unanimously reported that among CRC and BC patients with ostomies, sexual health may not be an immediate priority in their recovery as, from their clinical experience, they faced *greater obstacles to re-engaging in sex*. HCP spoke to the practical obstacles that patients faced when learning to live with an ostomy – significant changes that took

precedence over sexual re-engagement and fell lower in patients' list of priorities. As one social worker explained:

It's sort of like the focus becomes on survival... I often find when supporting people with their emotional health, it kind of gets put to the backburner a little bit for people, too, right? Because they're so focused on, 'Okay, I've got to get my treatment sorted, got to get this ostomy, [I've] got to learn to live with this ostomy, and then I'll worry about the, you know, how has this affected me psychologically and emotionally.

Several HCPs also suggested that the disruptions to self-identity and self-image imposed by the ostomy may account for this delayed re-engagement; acceptance of the ostomy and its impact on the patient's sense of self need to be addressed first; "[the ostomy is] sort of one more obstacle to get over... In the world of intimacy... and maybe for some people it takes a long time for them to even get 'round to thinking of themselves as a kind of sexual person again, who is going to have intimate moments." HCPs posited that the nature of the self-image concerns that arise among patients living with ostomies after cancer are different than those of cancer patients whose treatments do not typically necessitate an ostomy, such as breast cancer patients. HCPs described the different kinds of worries that arose with the ostomy appliance both in and outside of the bedroom, including the appearance, odor, and noise of the stoma, as well as the notion that the ostomy serves as "an external sign" of the cancer for themselves and their current or future partner(s). Perhaps most notably, when comparing the body image concerns of BC and CRC cancer patients with those of breast cancer patients, one participant interviewed posited that the *meaning* of the physical changes caused by cancer are distinct among patients living with an ostomy – representing the addition of an intrusive appliance versus the loss of a piece of one's sexual self – and in turn are processed differently:

... I don't know whether its women, you know their perception as their breasts being so important for their sexuality and their interaction with their partners, whereas the ostomy it just sits, 'it's just not even part of me', right? It's like this 'thing' and you know that's

what patients describe it as, this ‘thing’ – ‘I don’t even want, it’s not anything to do with me’. With breast patients, you know if they have reconstruction, or they could even have an implant, but they see that differently, as a different kind of, perspective I think on how they see that imaging of themselves... [whereas with the ostomy]... it’s absolutely foreign... ‘it just shouldn’t be there’ maybe they’re thinking, versus the breast as a loss and it was part of that sexual relationship or expression of sexuality, whereas this is sort of just come out of nowhere, the ostomy... this additional kind of appendage that we carry around... I just think [patients with ostomies are] such an interesting population of patients because I just get a sense with this population that much of their struggle is very internalized, that they don’t really share with a lot of their family, necessarily with their partners, that you know this is very much a personal identity kind of struggle for them...

Although this HCP, as a psycho-oncology clinician, benefits from having longer-term relationships with patients, she identified that the needs present among patients living with ostomies after CRC and/or BC can be so complex, particularly in terms of the challenges to their self-image, that sexual health is not a target of psychological intervention in her experience as other concerns take precedence. One of the other participants expanded on her thinking about body image and suggested that intimacy and sexuality could be more easily ignored in BC and CRC than in breast cancer because of the relationship of the meaning of the physical changes:

I think from a sexual, like non-anatomic, intimacy and sexuality perspective, people can ignore that—as unhealthy as it might be—people can ignore that for years, and they do... when you think about all types of life situations that make you go through these sexuality phases, you become very resilient to not be touched for X amount of time, and it doesn’t affect the fact that you can still go to work and do your job. But, so I think that’s probably what happens, as opposed to if a breast is removed, it’s front and centre. We’re talking about my sexuality. This surgery is involving my sexuality.

HCPs identified that from their clinical observations, patients with ostomies following CRC and BC typically take longer to be sexual again, relative to their counterparts recovering from other types of cancers that do not require ostomies. They perceived that greater practical and emotional demands in adjustment imposed by the ostomy resulted in patients placing less priority on sexual re-engagement or concerns about sexual health during their adjustment process, and suggested

this likely acted as a significant barrier to recruiting patients for the interventional study as this aspect of their recovery was not top of mind at the time they met with the HCP in hospital.

Relatedly, HCPs indicated that the *ostomy acts as both a barrier and catalyst* to raising the topic of sex among BC and CRC patients. The body image concerns that accompany many patients' adjustment to the ostomy can serve as an opening to raising the issue of sexual health post-ostomy; patients' expressions of dissatisfaction with body image cued some HCPs to talk to their patients about sex or, less commonly, patients connected body image to sexual health and raised the topic themselves. As a WOC nurse recalled, "We've had patients say, 'You know what? It's gross, I don't want to look at my partner.' I've seen people keep it a secret from their partner because they're worried about what they're going to think. And that just totally separates their ability to be physically close." These disclosures cued the WOC nurse to provide counselling around practical steps the patient could take to cope with their discomfort in intimate encounters. On the other hand, HCPs also suspected that the discomfort of the patient and HCP with regard to the ostomy can serve as a barrier to talking about sex, and in turn may have affected recruitment as the topic of sexuality would be avoided during clinical encounters. As the radiation therapist described:

I would say there's something different about [cancer patients with ostomies]. You know, just because I think ostomies in general, even though, you know, in healthcare we see lots of them and it's—it should be very normal—but I think there's always something that is a little bit, that people don't want to sort of, deal with. You know, because it seems very unnatural... if healthcare professionals feel uncomfortable, and feel like there's something, you know, kind of offensive in a way about intimacy with an ostomy—you know, if healthcare professionals have those prejudices, then I'm sure the patients also do.

Similarly, a front-line nurse shared that "some [patients] can't even look at it, so of course those patients may not be the easiest to talk to about their sexual health related to their stoma." These descriptions of clinical encounters in which the ostomy acted as either a catalyst or barrier to

addressing sexual health suggest that the presence of the ostomy may have played a role in HCPs likelihood of informing patients about the interventional study, for better or for worse.

It was also suggested by HCPs that *various facets of patients' and couples' identities* may have decreased their likelihood of participating in a psychosexual intervention after BC and CRC. They suggested that sexual orientation may play a role in patients' openness to discussing sexual health concerns, specifically among gay men. A WOC nurse and a front-line nurse both indicated that in their experience homosexual men with CRC prioritize sexual health and were more vocal in expressing their concerns related to sexual function and intimacy than other patients. As the WOC nurse explained:

I found one of the groups that was probably most forthcoming were gay men. And so people having rectal cancer, and having to have their rectum removed, and their form of sexual pleasure on the receiving end being anal intercourse, is huge. And so they were a group that that was a priority for them. That often came up first visit.

On the other hand, another HCP suggested that from her observations, gay men may be less inclined to express their sexual health concerns due to shame or perceived stigma about the sexual origins of their cancer:

I think the other thing about this site as well, which I haven't said about, but I think, you know, there could be a kind of viral aspect to it that some patients say with anal cancer, you know, they might feel that it's kind of related to some virus or sexual activity and that's one of the reasons they've ended up with cancer.... You know, say like gay men I think are more prone to you know anal cancer and those kind of things... could be some, you know, feelings around that... I mean I think there's a kind of guilt attached to it, or, you know, that there's something unclean about them generally....that they ended up with cancer.

Additionally, HCPs suggested that patients' and their partners' gender identities may have impacted their willingness to discuss sexual health but again there was no clear consensus among HCPs as to how gender may disproportionately enhance or hinder willingness to engage in such an intervention. Some HCPs indicated that, in their experience, discussing sexual health with



female patients was less welcomed than with males, while others suggested that male patients and spouses were more hesitant to have these conversations relative to their female counterparts. HCPs also indicated that many of their CRC and BC patients are in later stages of life and while they try to avoid stereotyping, they have found that sexual health is a relatively lower priority for patients in older age, especially when they are less physically fit; this leads HCPs to avoid the topic with such patients, fearing that “it would almost feel ridiculous to bring it up... almost insulting.” Moreover, HCPs suggested that offering psychosocial support – as in the intervention in question – to patients can be difficult as they may perceive the offer to mean that they are unable to cope effectively, and that patients’ help-seeking beliefs and sexual beliefs within their cultural and religious identities may compound their hesitation to seek an intervention focused on sexual health. Thus, patients’ and couples’ identities may have either helped or hindered their openness to engaging in the trial, and even if the trial would have been offered by the HCP in the first place.

Lastly, among CRC and BC patients, HCPs distinguished between *illness trajectories* that they believed could influence successful recruitment. The surgical oncologist suggested that those with temporary ostomies may be less inclined to participate, opting instead to wait out the period with the ostomy, while those with permanent diversions may be more inclined to engage in interventions because the ostomy is a life-long adjustment:

People who have a stoma for six months, or eight months, or a year, they’re probably thinking like, you know, ‘I’ll go on Tinder once this thing’s reversed.’ Right? As opposed to someone who’s got a permanent stoma who maybe once they’ve figured it out, you know, now they’re starting to do irrigation, for example. And they’re starting to stop wearing a pouch and just put a thing on it, and like, now they’re starting to get back into their world, and integrate into society with this thing.

One WOC nurse also highlighted how with surgical advancements, fewer patients are requiring permanent diversions and thus there may be a fewer number of potential patients who would

want to participate in the intervention. This WOC nurse and the radiation therapist also suggested that patients living with ostomies due to cancer as opposed to other bowel diseases like ulcerative colitis or Chron's disease may have more complicated relationships with the ostomy and thus be less inclined to participate as they focus on their survival:

You know, you're looking at a population—we're going to focus with cancer—it's different with people with other conditions that require an ostomy, for example inflammatory bowel disease, people are born with congenital anomalies. They either get their stoma early, or it's temporary, or if they have a physical condition like inflammatory bowel, Crohn's, or colitis they know that maybe down the road that could happen. It's not a brand new thing. When you're dealing with a cancer population, you're not only dealing with their diagnosis... but you're dealing with the fact that now they have to have this altered body function... So I would say the priority at the beginning for a lot of people is just, 'Okay, what are you going to do about my cancer?'

Within the two cancer groups targeted for the intervention, a front-line nurse suggested that relative to BC patient, CRC patients “cope much better, because they have different options to cover [the ostomy], with emptying the pouch, putting the small pouch, and put some odour to prevent—you know, the deodorant to prevent the odour.” In contrast, a WOC nurse suggested the opposite, that

[The] colorectal population can have other aspects [like metastases], whereas I found the urology patients [are] more [like]: 'I have bladder cancer, maybe not metastases, and I'm ready for life, because [it's having] my surgery and I'm right back. I'm recovering, and I'm better.' So that's why I always kept saying the urology patients for me always seemed to be more receptive, quicker...

Overall, HCPs suggested that the type of ostomy and the circumstances that lead to the creation of the stoma could influence the desirability of a sexual health intervention for patients with ostomies. Patients living with permanent ostomies and for noncancerous reasons were viewed as more likely to participate, while there were mixed opinions about the readiness of CRC versus BC patients in engaging in a sexual health intervention.

## Intervention Design Barriers

HCP also identified aspects of the intervention design that they believed contributed to barriers to recruitment. According to HCP, eligibility criteria were restrictive. One front-line nurse and one WOC nurse agreed that the patient being in *active cancer treatment as exclusion* was prohibitive to the participation of patients who may have been otherwise suitable for the study. They reasoned that some individuals whom they treated were ready for the intervention, despite being in the midst of receiving chemotherapy. As the WOC nurse explained:

... And that was the big thing: the time. Because for me, it's too bad that they had to be in a certain time bracket. Because for a lot of times, part of even someone having treatment, and they're recovering, part of that is that intimacy. And even if they may be fatigued or something, if they've recovered from the surgical part, that's when intimacy is starting to be important. But we're telling them, it's got to wait till you're finished your chemo, before we can have that for you.

The radiation therapist posited that recruitment may have been more successful if it were open to inclusion of individuals living with *ostomies for reasons other than cancer*, due to the possible stigma experienced by patients with cancer:

I think just having it open to anybody with an ostomy, you know, might have been useful. I think definitely people would have been more open to it, because I think having cancer, you know, this type of cancer, and having it end up with an ostomy, people probably feel different about it than, you know, from other diseases.... like I said before, you know, just say if people have got the disease through, you know, kind of like sexual practices or viruses or things like that, then they probably feel kind of guilty or something. I'm not really sure.

Importantly, about half of HCPs suggested that the *couples-based nature of the intervention excludes singles* and thus was a significant impairment to the intervention recruitment. HCPs spoke to the challenge of recruiting not one but two individuals, for example one of the referring clinician participants indicated that two female patients had expressed interest in participating but neither of their husbands were willing. HCPs also explained that patients may not feel comfortable discussing sex with their partner present, for example one WOC nurse explained

that some patients request their partner leave the room when she raises the topic of intimacy and sexual health during a clinical encounter “because [the patients] felt that it was kind of *their* issue” as opposed to an issue shared by the couple. Another HCP described that it was “not infrequent” for some of his patients diagnosed with cancer (but not necessarily CRC or BC) to report that they were not engaging in sexual intercourse when asked in the presence of their partner but, once alone, disclosing to the HCP that they were having sex outside of the relationship/marriage. HCPs identified that recruitment may have been more successful in meeting the needs of patients if the intervention could have been adapted to be delivered to patients or partners individually so as to allow just one or the other to participate. Moreover, HCPs suggested that offering the intervention to patients who were not currently partnered and who are experiencing distress related to their sexual health, such as concerns of when and how to disclose the ostomy when dating, could have also been helpful in increasing recruitment.

Importantly, one physician posited that *in-person is preferred to Internet* delivery of healthcare services by patients and could have acted as a barrier to engagement. Although he was alone in suggesting this among the HCPs, he was adamant that patients place more value on meetings for which a HCP has set aside a “dedicated time” in-person to meet. He suggested that Internet-delivery is not as engaging for patients and HCPs and both are vulnerable to distraction in their immediate environment. The HCP suggested that as in-person meetings assume the full attention of HCPs, they are generally viewed as being more credible to Internet-delivered interventions. Moreover, he pointed out that online resources are susceptible to technological failure and user error and illiteracy, which may be particularly relevant among older aged cancer patients. According to this HCP, “if patients are going to dedicate their time to participation, the intervention should be in person” and stated that potential barriers to in-person engagement,

including travel to the hospital and parking fees, could be mostly negated by providing couples with a parking voucher.

## **Discussion**

The results of the thematic analysis revealed several potential barriers to recruitment, from the perspective of HCPs who treat the target patient population. Barriers were identified at the level of the system, the provider, the patient, and the intervention. These barriers, summarized below, are largely consistent with previous research on general trends in addressing sexual health in oncology as well as previous examinations of recruitment challenges for interventional trials targeting sexual health after cancer. The current investigation sheds light on clinical and research considerations for the implementation of future trials of psychosexual interventions for patients after BC and CRC.

At the systemic level, the absence of a formal process to assess patients' sexual health and to refer them to appropriate resources meant that how, when, and even *if* the topic of sex was raised within a clinical encounter was left to the discretion of each HCP. This stands in contrast to the use of a standardized tool to screen other metrics of health quality of life (e.g., pain, depression, and fatigue) at each visit to inform the prioritization of these issues during the encounter. With the lack of a formal process to address sexual health, some HCPs noted that they waited for patients to raise the issue of sexual health themselves. Patients, however, rarely initiate these conversations due to embarrassment, poor rapport with the HCP, and/or the perception that HCPs are uninterested and unprepared to address their concerns (Averyt & Nishimoto, 2014; Fitch et al., 2013a). Instead, patients have expressed a preference for HCPs to initiate such discussions (Flynn et al., 2012; Traa et al., 2014). The failure to establish standardized procedures with regard to assessing and addressing sexual health may be a

reflection of the system's "siloe" organizational structure, as labelled by HCPs, that is characterized by distinct boundaries between areas of practice and limited coordination and communication among providers. The notion that healthcare is fragmented across disciplines and between organizations within the province of Ontario and in cancer care due to increased specialization and organizational structures is not new (Buchman et al., 2018; Evans et al., 2014; MacLeod, 2003; Sinding et al., 2013). However, the intervention's target population seemed to be at particular disadvantage within this system, as HCPs described a culture of care that allocates limited resources and attention to the sexual health of patients with cancers, like BC and CRC, that are not "obviously" related to sexuality; a pattern that has also been noted related to research in the area (Gilbert et al., 2009). Evidence of this disparity in practice was noted by HCPs noted in an absence of clinical supports, educational materials, private spaces, and sex-positive signage in CRC and BC clinics. Relative to those treated in other site groups, patients within this population did not receive the normalizing effects of such resources.

It is possible that the disparity in attention paid at the systemic level to sexual health care in CRC and BC influenced the poor accrual rates for the trial under study. As was suggested by one HCP, since sexual health is not part of an established dialogue between the patient and HCPs in the BC and CRC clinics, an offer to participate in a trial of a psychosexual intervention may be experienced as unexpectedly intrusive by patients. To facilitate patient-provider communication about sex, it has been recommended that tools for screening sexual health concerns within this patient population be integrated early into treatment and used consistently across all stages of the cancer experience (Averyt & Nishimoto, 2014), but unfortunately no instrument has been identified as the "gold standard" for screening for sexual dysfunction in cancer (Bartula & Sherman, 2013) and, as has been pointed out by Buchman et al. (2018), "without standardized

system-level measures that cut across care settings, there is little guidance, accountability, or incentive to integrate care” (p. 2675).

Still at the level of the system, time spent with the patient in terms of length of visits and an ongoing care relationship was viewed as posing a further barrier. Consistent with previous research, short visits challenged HCPs’ ability to address sexual health amongst other areas of quality of life (Fitch et al., 2013b; Maree & Fitch, 2019; Traa et al., 2014; Ussher et al., 2013), particularly with CRC and BC patients with ostomies because their needs were viewed as more complex and time intensive relative to other cancers. The ability to raise the topic of sex within the context of a trusting ongoing care relationship was viewed as preferable to most HCPs, for both their own level of comfort and that of the patient. However, within the nursing discipline, the model of care was such that few relationships with patients were long-term. This presented a difficulty in terms of referring patients to the study as HCPs may have only one clinical encounter in which to inform patients of the study – an encounter that may come at any point in their cancer journey, not necessarily when they were complete or nearing completion of treatment and eligible to participate. Relatedly, HCPs had mixed perceptions on the appropriate time to inform patients of the interventional trial; some deeming the subject inappropriate early in treatment when the focus was on survival, while others believed it could promote hope of future support. Either way it was recognized that patients may forget about the opportunity if they were not reminded post-treatment. Interestingly, an oncologist who was in a position of providing medical care to patients over the course of treatment and in follow-up expressed concern that informing them of the trial could be potentially coercive to participant enrollment, reasoning that patients may fear negative consequences in their long-term care with him, if they were to decline or withdraw; although alone in this study, his belief is shared by other HCPs in

the literature (Nipp et al., 2019). Therefore, while our intention was to capitalize on HCPs' long-term relationships with their patients to enhance the perceived legitimacy of the trial and, in turn the likelihood of couples' participation (Fredman et al., 2009; Jennings et al., 2014), this plan was largely unsuccessful because the HCP-patient relationships either did not exist or they had the reverse effect in serving as a barrier to discussing the trial at all.

Moreover, HCPs described barriers at the level of the individual provider or their discipline to addressing sexual health and informing patients about the interventional study. The majority of HCPs identified sexual health as a gap in their training and education, with psychosexual concerns (e.g., intimacy, body image) and sexual concerns of patients belonging to the LGBTQ+ community as particular areas of perceived incompetence. HCPs' predictions that they would be ineffective in providing care or appropriate referrals was prohibitive of their engaging with patients around issues of sexual health. Beyond professional competencies, others also discussed a personal discomfort in addressing sexual health, due to their own sexual insecurities, values, and beliefs – with some HCPs noting outright refusals to discuss the topic among their colleagues. These findings are consistent with previous research that demonstrates that insufficient training, low confidence, and discomfort are significant obstacles to oncology HCPs in initiating conversations about sexual health with their patients (Fitch et al., 2013b; McLeod & Hamilton, 2013; Traa et al., 2014; Ussher et al., 2013).

While some HCPs expressed a desire to develop their competency in this area, they lamented the lack of time to do so. The availability of an information sheet about the study was reportedly helpful to HCPs in initiating conversations with their patients and/or their partners about sex. While these conversations did not always result in referrals to the study as anticipated, from a clinical standpoint, they sometimes led to an opportunity for the provision of sexual



health care (e.g., education, referral, establishing working dialogue), further illustrating the utility of written materials and resources in normalizing concerns among this population.

Notably, one HCP – a surgical oncologist – expressed that he considers any sexual concerns that are not directly related to surgery as outside of his professional scope, and therefore not something he would discuss for fear of crossing a boundary within his relationship with the patient. The belief among HCPs that raising the topic of sex, beyond the medicalized (e.g., changes in sexual functioning), is risky and inappropriate within the established care relationship with the patient has been reported elsewhere (Hordern & Street, 2007; Traa et al., 2014).

Unfortunately, these HCP barriers to initiating conversations about sexual health may prohibit the opportunity for patients to receive referrals to the supportive resources they need in their sexual recovery. Previous research on barriers to engaging women in a trial of a sexual health intervention following anal and rectal cancer suggests that referrals from HCPs are instrumental to enhancing patient recruitment such that the normalizing effect of a HCP raising the topic of sex with patients within the privacy of the clinical context improves the likelihood of a willing response from patients toward participation in the research (Jennings et al., 2014). Ironically, the very paucity in clinical attention afforded to sexual health in oncology that served as the impetus for the interventional trial was also a barrier to its implementation. It was hoped that the availability of a psychosexual intervention within the hospital would encourage HCPs to feel comfortable raising the issue of sexual health with their patients, but unfortunately this appeared to only be the case for one of the HCPs interviewed.

At the level of the patient, HCPs identified several ways that the target population for the intervention was particularly difficult to recruit for a psychosexual interventional trial, relative to other site groups. They suggested that CRC and BC patients' sexual adjustment was delayed and

prolonged compared to other cancer patients due to the myriad of other concerns imposed by the ostomy (e.g., managing dietary changes, establishing new hygienic practices, assault on sense of identity) and may not be of primary concern to patients during their more acute care with HCPs at the hospital. While each patients' adjustment is unique, research supports that individuals with ostomies prioritize areas of daily functioning over sexual well-being in their adjustment process to the device, with sexual adjustment becoming increasingly more important several months post-operatively as opposed to early in treatment (Carlsson et al., 2010). As was also recognized by the HCPs in the current study, both the psychological and physiological aspects of these patients' sexual recovery is further complicated by the impact of the ostomy on their embodied sense of self and may warrant direct intervention first or concurrently (Benedict et al., 2016; Kimura et al., 2013; Ozturk et al., 2015; Ramirez et al., 2010; Smith et al., 2017; Thorpe et al., 2009). Consistently, other trials of sexual interventions for individuals and couples after CRC have reported that lack of interest and time are among the most common reasons provided by refusers for declining participation (Jennings et al., 2014; Reese et al., 2014; Shaffer et al., 2018) and a survey of individuals with ostomies revealed that sex and intimacy ranked at the bottom of their list of priority research areas relative to other aspects of quality of life, including leaking pouch, hernias, pain, and body image (Hubbard et al., 2017). As has been suggested by others (Fredman et al., 2009; Reese et al., 2014; Shaffer et al., 2018), the intervention under study was designed to be brief and offered to couples following active treatment, when sexual health was expected to be of greater clinical priority to patients. However, in practice, HCP reported that informing patients of the trial when they were completed treatment was not always possible given their model of care or lack of ongoing care relationship.

HCPs in the current investigation also identified that, while the presence of an ostomy could facilitate conversations about body image with the patient that led to the topic of sex, its presence could also generate discomfort and act as a barrier to such discussions. Patients' perceptions of disgust toward stomas and fecal incontinence and their sensitivity to stigmatizing reactions by others can lead to avoidance of discussing their concerns with HCPs (Norton, 2004; Smith et al., 2007); in turn HCPs have been recommended to take heed not to make any verbal or nonverbal communications of disgust when caring for patients' stomas (Burch, 2005). It stands to reason that the stigma and shame surrounding ostomies presents an additional complexity in openly discussing the already taboo nature of sexual health that, itself alone, has been found to prohibit participation in psychosexual interventions for patients and couples after cancer (Jennings et al., 2014; Reese et al., 2018). Additionally, HCPs in the current investigation suggested that the type of ostomy (e.g., temporary versus permanent), the type of cancer (e.g., CRC or BC), and the reason for the ostomy (i.e., in the treatment of cancer vs. non-malignant diseases) may influence patients' willingness to participate in an interventional trial, with the speculation that those with permanent ostomies and those having an ostomy for non-cancerous reasons would be more receptive to participation in such an intervention. Research suggests mixed support for these HCPs' speculations. While patients with permanent diversions appear to have more sexual problems (Ozturk et al., 2015), patients who have temporary ostomies (versus permanent) (Smith et al., 2009) and those who have ostomies for non-malignant reasons (versus due to cancer) (Krouse et al., 2007) have poorer overall adjustment to the ostomy. That being said, these trends are difficult to predict as greater needs do not necessarily correlate with participant enrollment (Reese et al., 2018) nor with patient readiness to seek help (Fitch & Maamoun, 2016; Fitch & Steele, 2010).

HCPs also posited that aspects of patients' and couples' identities, including sexual orientation, gender, age, religion, and culture, may have influenced trial recruitment. Specifically, they suggested that these aspects of identity may impact patients' and couples' openness to participate and some described how these facets of personhood may influence their likelihood of informing patients of the trial. Previous research demonstrates that older adults are underrepresented in clinical trials in cancer generally (Ford et al., 2008; Kornblith et al., 2002) and age was identified as significant factor in recruiting women for a sexual intervention after rectal and anal cancer, which was suggested by the authors to be due in part to a generational discomfort among older women in discussing sex (Jennings et al., 2014). Gender differences have also been found in acceptance rates for a sexual health intervention for individuals after rectal and anal cancer, with a higher proportion of eligible men declining (Shaffer et al., 2018). While the current investigation suggested these differences to be highly individualized among patients and HCPs with regard to the trial under study, it is relevant to note that research demonstrates physicians are unlikely to offer a trial to patients whom they do not believe will complete the study procedures (Nipp et al., 2019).

Lastly, HCPs also identified barriers within the intervention and trial design that may have impacted couple recruitment to the study. HCPs suggested that the inclusion criteria were too restrictive and that opening the trial to patients who are undergoing active treatment for cancer as well as to patients living with ostomies for reasons other than cancer would have increased participation and would have been appropriate. While it is certainly reasonable to assume that more inclusive criteria would have expanded the potential pool of participants, it is unclear the degree to which this would have increased participation, especially given these patients' prioritization of sexual health during active treatment (Carlsson et al., 2010). HCPs also

suggested that the intervention would have benefited from flexibility in its application to individuals (e.g., partnered patients whose spouses did not wish to participate, or to patients not currently in a relationship). Average recruitment rates for couple-based interventional trials in cancer have been reported to be lower than for individual-based interventions, with lower rates for interventions focused on communication and those requiring patients and partners to participate together (Fredman et al., 2009; Regan et al., 2013). In their examination of a pilot trial of a four session telephone-based couples' intervention for enhancing intimacy after breast cancer, Reese et al. (2018) similarly identified partners' non-interest as a barrier to participation and posited that the option to apply the intervention to individuals (patients and partner alone) and couples would have enhanced recruitment. Additionally, one HCPs suggested that the Internet delivery of the intervention was likely a barrier for couple engagement as it was the provider's impression that patients perceive virtual healthcare services as less legitimate or valuable than face-to-face interactions in the hospital. While preference for Internet-delivered health information among individuals with chronic health conditions does appear to vary with age, education, and current use of technology (Gordon & Crouch, 2019), the HCP's suggestion is inconsistent with a systematic review of Internet-based interventions for enhancing quality of life after cancer that reported patient preference for online interventions (Corbett et al., 2018), breast cancer patients' reported preference for an informational website as the mode of information delivery about sex (Reese et al., 2018), and promising trials of Internet-delivered interventions for sexual health with cancer patients (Cullen, 2019; Hummel et al., 2017; Schover et al., 2013). Moreover, this format for delivery was chosen in the intervention to eliminate travel barriers and enhance inclusion of participants living in rural areas (Ford et al., 2008; Shaffer et al., 2018).

## **Limitations**

The current investigation is limited by the small sample size of HCPs, with representation of only 1-3 providers in any one discipline. It is possible that the HCPs who self-selected to participate in the current investigation were generally more open to discussing sexual health than those who declined, although this information was not assessed. Moreover, HCPs differed in their degree of involvement in the recruitment for the intervention, with some providers having only learned of the intervention through researchers' efforts in soliciting HCP referrals and others being consulted in the development and design of the interventional study. All but one of the HCPs worked at the host hospital for the trial, limiting our ability to generalize the systemic barriers beyond this particular institution.

## **Clinical and Research Implications**

Within the context of the current investigation, it is reasonable to extrapolate that these systemic, HCP, and patient-related barriers to addressing sexual health within routine clinical encounters would likely have reduced the frequency with which HCPs informed patients and/or their partners about the opportunity to participate in the trial and thus ultimately contributed to the limited amount of HCP referrals to the study. Given the reported benefit of the information sheet in mitigating HCP discomfort in broaching the topic of sex, future researchers should consider providing HCPs with written material about the study to facilitate the beginning of the referral process. Scripting the language of the information to include information about weighing risks and benefits of participation (Albrecht et al., 1999; Nipp et al., 2019) and choosing words like 'program' as opposed to 'treatment' or 'therapy' could be helpful to participant accrual (Fredman et al., 2009). Although to enhance the likelihood of HCP referrals, physicians interviewed in the current investigation also suggested that study coordinators be present within

clinics to provide reminders to HCPs about the ongoing trial recruitment as well as to meet with couples, as a neutral party in their care, to inform them about the study. Other trials and investigations of trial recruitment barriers have incorporated such strategies or recommended them (Fredman et al., 2009; Jennings et al., 2014; Kornblith et al., 2002; Mahmud et al., 2018; Reese et al., 2014) and it has been suggested that patient navigators are particularly well positioned to play a role in this process (Nipp et al., 2019). Moreover, future trials for sexual health interventions in BC and CRC may also consider recruiting patients later in their treatment recovery, through their family physicians or community care agencies that typically have longer-standing and established relationships with patients.

Recruitment efforts may also be tailored to target particular subgroups within the CRC and BC patient population that are vulnerable to non-inclusion, including older adults, members of the LGBTQ+ community, and men. The current investigation also suggests that future iterations of the intervention may benefit from targeting patients' body image more explicitly (in advance of soliciting participation in a psychosexual intervention), which was believed to be of primary concern to this particular patient population within their overall process of sexual adjustment and which has been suggested to act as a barrier to participating in sexual health interventions among women after rectal and anal cancer (Benedict et al., 2016). Relatedly, the development of future psychosexual interventions for BC and CRC patients with ostomies would benefit from the inclusion of patients as co-investigators to provide input on the intervention content, timing of the intervention across the stages of the disease, and delivery-format, such that it may better match the needs of its target population and result in increased uptake (Corbett et al., 2018).

Still, researchers' best efforts to trial and establish interventions for sexual health within

standard cancer care will likely continue to be challenged by systemic barriers that create a culture in which sexual health is largely ignored, despite calls from government agencies to address this area of oncology (Barbera et al., 2016). As Shaffer et al. (2018) note, “regardless of treatment efficacy, when the treatment cannot be reliably carried out within a particular healthcare system, the potential scale of intervention benefits to the population served is diminished” (p. 1082). Therefore, along with innovation in sexual health interventions for cancer patients and their partners, there needs to be a concurrent cultural shift to bring issues of sexual health to light within oncology care, a process which the current research suggests may benefit from the inclusion of: (1) initiatives to increase positive sexual messaging across cancer centres to normalize these concerns, especially among disease sites that do not directly affect sex or sexualized organs (such as breast and prostate cancers), (2) dedicated time for HCPs to engage in education that de-mystifies and de-stigmatizes sexual health issues and offers practical advice on talking about sexual health with their patients, (3) the establishment of screening practices and team-based procedures for identifying patients with sexual health needs (e.g., use of standardized tools for screening sexual distress at each visit) and referring them to appropriate resources, which can include information about current research trials, and (4) the creation of private spaces to conduct sensitive conversations about sex within CRC and BC clinics. Once the above practices are in place, then increased financial and labour resources dedicated to the creation of educational materials and supportive resources targeted toward BC and CRC patients may have greater likelihood of succeeding and becoming part of standard oncology practice.



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## **Chapter 6**

### **Conclusion**

As a whole, this body of work aims to begin to address the underserved sexual health care needs of CRC patients with ostomies and their partners. These efforts respond to the “vital” recommendation put forth by Barbera et al. (2016) in their report for Cancer Care Ontario and similar expressions by CRC patients and their partners (Traa et al., 2014) for ongoing conversations about sexual health initiated by healthcare providers. Over the course of the three studies, knowledge and new learning about the challenges in bridging the needs, recommendations, and treatment for sexual health in CRC care can be gleaned.

In Study 1, a grounded theory analysis (Glaser & Strauss, 1967) of dyadic interview transcripts with couples adjusting to life with a permanent colostomy following rectal cancer was undertaken in an effort to better understand the sexual health challenges faced by these couples and the ways that they attempt to cope with them. The results of the grounded theory analysis revealed that, although couples demonstrated at least some degree of natural resiliency to the sexual changes imposed by the colostomy and cancer, they still experienced these changes as challenges and expressed a lack of support from healthcare providers in their coping. Moreover, by taking the approach of studying the dyad, the results suggested that facilitating conversations with couples about this topic that is so often left unspoken may encourage learning and deeper appreciation for one another.

Study 2, in turn, evaluated a novel Internet-delivered couples-based intervention to support the sexual and intimate re-adjustment to an ostomy after colorectal cancer. The two-session intervention took a resilience and strength-focused approach to facilitating conversations with couples about the sexual changes they had experienced to encourage mutual learning and

identification of dyadic strengths for coping and, ultimately, enhance couples' sense of self-efficacy in coping with sexual change. The original intent of this study was to conduct a randomized-controlled trial of the intervention but due to significant challenges in recruitment, only two couples participated. In recognition of these couples' valuable contribution, an embedded single-case study was undertaken instead. The intervention was considered the 'case' and main focus of inquiry, and the 'parts' or core characteristics of the intervention were considered the 'embedded units of analysis.' Couples' post-treatment interviews and questionnaires as well as the facilitator's observations were the sources of information about the intervention (and its embedded parts) as well as its context. Couples' feedback demonstrated preliminary information about the acceptability and feasibility of the various components of the intervention from the perspective of its users but suggested that couples will complete the exercises only to the degree that they feel ready; importantly poor support otherwise received at the hospital around ostomy adjustment may contribute to a lack of readiness in addressing sexual health. The results of the case study suggest that the intervention may be one way of filling in gaps in CRC and ostomy care specific to intimacy and sexuality while simultaneously facilitating the coordination of resources through the provision of relevant referrals, with each potentially enhancing the other. In other words, the program may be well positioned as a stepping-stone for couples in accessing longer-term psychosocial supports when needed.

Lastly, study 3 was undertaken as corollary to the unsuccessful pilot RCT, with the aim of identifying barriers to recruitment. Given the conundrum concerning low recruitment, a decision was made to investigate potential challenges to engaging this patient-population in the pilot RCT from the perspective of HCPs rather than patients themselves. This study capitalized on the insights of HCPs who work with the target population on a regular basis and could draw

upon their professional expertise and clinical experience within the hospital setting to identify potential systemic and patient-related obstacles to recruitment. A thematic analysis (Braun & Clarke, 2006) of interview transcripts was conducted and resulted in the identification of systemic, health care provider, patient-related, and intervention-specific barriers to recruitment to the pilot RCT. As emerging health policies and guidelines highlight the need to address sexual health in cancer care, the results also have broader applications in the advancement of care in this area. In particular, the results provide further evidence of the relative disadvantage of the CRC and within the medical system regarding sexual health and the need for a cultural shift to support research aiming to level this disparity.

As a whole, the three studies echo this notion by highlighting the challenges that researchers and medical and allied health care professionals face in meeting patients' demands for care as well as new standards and guidelines for clinical practice, when the medical system does not necessarily support their ability to do so. The work implies that further efforts are needed on a systemic level to educate healthcare providers within their respective schools of training about sexual health so as to normalize the provision of such care as part of standard clinical practice. It also highlights the need for greater allocation of resources, both financially and practically, toward the provision of sexual healthcare in CRC to support the establishment of coordinated screening and evidence-based treatments. At the same time, the studies are a reminder to researchers, clinicians and policy-makers alike that although patients identify challenges and unmet care needs in their treatment and recovery, their identification does not necessarily translate to seeking or accepting support or treatment (Fitch & Maamoun, 2016; Fitch & Steele, 2010). As such, the studies also point to a role for the patient (and their partner) in

informing research and clinical initiatives designed to support couples' sexual and intimate adjustment to an ostomy after CRC.

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## Appendix A

### *Third-Order Categories of Couples' Sexual Adjustment to a Permanent Ostomy After Rectal Cancer With Their Defining Properties and Counts of Couple Endorsement*

Third Order Category	Property	<i>n<sub>c</sub></i>
Blow to function and identity	Threat to sexual function	5
	Intimate anatomical changes	9
	Painful effects of treatment	2
	Lowered libido	4
	Always liked sex...	5
	Avoid flaunting function	1
Each in their own time	Post-treatment hiatus/Slow re-integration	3
	In no rush	3
	Getting to work right away	1
Thinking 'big picture'	Keeping 'it' a priority	5
	We're more than sex	7
	Bound to happen/other factors at play	6
	Pre-existing sexual concerns	3
	Hopeful yet realistic thinking	6
Talking together and with others	Open communication	4
	Finding humour	7
	Ignorant or unresponsive doctors	6
	Appreciative of medical understanding	4
	Consulting and comparing with peers	6
	Learning through telling their story*	4
	Varying willingness and readiness*	11
Expanding and celebrating our sexual repertoire... or going without	One "last hurrah!"	2
	Grateful for some maintenance	2
	New and old forms of sexual activity	2
	Seeking out assistive devices	7
	Intimacy is more than sex	8
	No way to modify	2
Repairing marred body image	A fault in me	4
	Unparalleled self-consciousness	4
	Covering my embarrassment	4
	Turning the "ugliest thing" into something "quite attractive"	6
	Irrigation as a saving grace	3
Partners' (dis)comfort	Private worry	3
	The ostomy doesn't matter	7
	Uneasiness around stoma	2
Acceptance is essential, but not everything	Your beauty is intact	4
	No need to cover yourself	5
	Makes all the difference	4
	No matter partners' support	3
	Feeling shut out	1



## Appendix B

### **‘Mini Manual’: Internet-Delivered Intervention for Re-Adjustment to Sexual Intimacy With an Ostomy After Colorectal Cancer**

#### **Theoretical Underpinnings of the Intervention: A Focus on Couple Resilience**

Reid and Ahmad (2015) define dyadic resilience as “the process by which partners can jointly assimilate and accommodate to fluctuating circumstances over the lifespan of their marriage in a way that maintains and enhances the integrity of their marriage” (p. 140) while Singer and Skerrett (2014) define resilience as “the ability to bounce back after challenges and to learn and grow from adversity” (p. 21). Accordingly, couples’ sexual and intimate resiliency following CRC and ostomy surgery would hinge on their ability to assimilate and/or accommodate the physical and psychological changes imposed by the cancer and ostomy, while learning about and growing/enhancing the integrity of their sexual and intimate relationship. Unfortunately, research suggests that many of these couples are unsuccessful in maintaining or enhancing the integrity of their sexual and intimate relationship, as illustrated in patients and partners reporting low frequency or complete cessation of sexual activity following CRC and the colostomy surgery (Manderson, 2005). This begs the question: What is it that allows couples to be resilient and can we enhance that which is needed for resiliency so that couples are better able to accommodate changes to their sexual relationship?

#### ***“We”-ness Fuels Resilience***

Research in couple resilience has supported the notion that couples create a mutual identity, or “We-ness”, through each partner’s personal identification with the relationship (Fergus & Reid, 2001; Reid et al., 2006; Reid & Ahmad, 2015; Singer & Skerrett, 2014). For the relationship to function, partners must integrate their individual biological (e.g., genetics, neurobiology, hormones, sex assigned at birth), psychological (e.g., temperament, personality,

ways of thinking), cultural (e.g., values, beliefs), and social systems (e.g., ways of communicating, social role scripts, attachment style) in a mutually beneficial way (Fergus & Reid, 2001; Reid & Ahmad, 2015). This process requires a re-organization of each partners' sense of themselves to include being part of the relationship or "We" (Reid & Ahmad, 2015). Importantly, the creation of a couple identity does not denote the loss of partners' personal identities (i.e., both "I"s), but instead the "We" maintains and enhances each individual's personal identity and sense of self, as within the context of the supportive relationship each partner is encouraged to express their needs and grow as an individual (Feeney, 2004, 2007; Reid & Ahmad, 2015; Singer & Skerrett, 2014). Thus, "We-ness" is conceptualized as more than the joining of two individuals (i.e.,  $1+1=2$ ) but instead as an emergent phenomena or 'third entity' that is the result of two individuals co-constructing a shared identity by incorporating one another's perspectives into their own (i.e.,  $1+1 = 1+1+1$ ) (Reid & Ahmad, 2015; Singer & Skerrett, 2014; Taibbi, 2009). A sense of security, empathy, respect, acceptance, pleasure, humour, and shared meaning and vision are proposed as qualities that work systemically to allow for the creation of a "We" identity (Singer & Skerrett, 2014; Skerrett, 2015).

Singer and Skerrett (2014) suggest that "We-ness" exemplifies a couples' resilience in that it "consists of a capacity for working together, interpersonal sensitivity, and generosity, as well as a willingness to set boundaries and give space with a confidence that both separate and coordinated action will lead to mutual benefit" (p. 21). They suggest that it is a "shift of consciousness" (p. 21) from individual needs to the needs of the relationship that allows couples to access their relational strengths to overcome, learn, and grow from challenges (Singer & Skerrett, 2014). When partners share a sense of "We-ness", they mutually benefit from understanding themselves and their partner and they view the relationship as an extension of

themselves (i.e., part of their self-concept) (Reid et al., 2008; Reid & Ahmad, 2015). As a result, each partner is personally invested in making the relationship function and motivated to engage in the processes (e.g., empathy, perspective taking, respect, acceptance) that cultivate a sense of “We” (Reid & Ahmad, 2015; Singer & Skerrett, 2014). Consistently, research on enhancing “We-ness” therapeutically supports an association between the degree of a couples’ mutual identity and their relationship satisfaction, commitment, empathic attunement, and interpersonal processing (Ahmad & Reid, 2016; Reid et al., 2006, 2008). Most relevant to the current investigation, partnered women’s degree of identification with their relationship was associated with better psychosocial adjustment during their treatment for breast cancer; this association was mediated by coping self-efficacy such that a greater sense of mutual identity was associated with a greater confidence in their ability to cope with the cancer and in turn, predicted lower emotional distress and higher functional well-being (Ahmad et al., 2017).

Research in couple’s therapy suggests that engaging couples in conversations about their relationship can help build an awareness of their mutual identity and their relational strengths, which they can then draw upon in times of distress. By encouraging couples to take a participant-observer stance when discussing their relationship, partners can articulate and make explicit – perhaps for the first time – their implicit knowledge and assumptions about the relationship (Fergus & Reid, 2001; Reid et al., 2008; Reid & Ahmad, 2015). Such conversations about their “relational epistemology” can lead partners to an awareness about one another’s thoughts, feelings, and actions within the relationship and a better understanding of unhelpful dynamics that require adjustment in light of new contexts or life challenges (Reid & Ahmad, 2015, p. 142). Similarly, by co-narrating stories about their experiences in overcoming challenges *as a couple*, partners can come to view stressors as occurring to “us” as opposed to either partner

individually, motivating them to work together to solve problems (Fergus & Skerrett, 2015; Singer & Skerrett, 2014; Skerrett, 2015). Skerrett (2015) describes a key quality of “We”-stories as a “reintegration of relational wisdom” (p.10), which refers to couples’ abilities to reflect upon and learn from their experiences of successfully overcoming challenges. Gaining such awareness allows couples to build a resource of adaptive responses that they can draw upon and strengthen as they encounter challenges across the course of their relationship (Skerrett, 2015). In this vein, Fergus & Skerrett (2015) propose that resilience can be built or strengthened in the same way as a muscle; both require stress in order to grow and assume some level of pre-existing resources.

### ***The Role of Intimacy in Sexual Resilience After Cancer***

Within the oncology literature, Beck, Robinson, and Carlson (2013) identified characteristics that distinguished couples who were resilient – successful in adapting to sexual challenges – from those who were not and proposed a model of sexual resilience, the Physical-Pleasure Relational-Intimacy Model of Sexual Motivation (PRISM). By using grounded theory to analyze interview transcripts of 17 couples’ experiences following prostate cancer, they found that couples engaged in sexual activity for two main reasons: (1) physical pleasure and (2) relational intimacy. Couples who valued sex for relational intimacy were more successful in adjustment to sexual changes after prostate cancer than couples who valued sex mainly for physical pleasure. The model proposes that in valuing sex for relational intimacy, couples are less invested in the physical outcome of their sexual encounters, and thus better able to accept challenges as they arise, maintain flexibility in finding solutions to these challenges, and persist in engaging in sex despite these challenges (Beck et al., 2013). Valuing sex for intimacy also helps couples to avoid a negative feedback loop in their sexual relationship; less pleasurable sexual encounters are not regarded as failures, at least not completely, because emotional

closeness is still derived, and couples are in turn less inclined to view these occurrences as predictive of their future sexual activity.

An exercise in which couples “plot” their motivations for engaging in sex on a continuum from high to low for each dimension of motivation (i.e., physical pleasure and relational intimacy) was developed in accordance with the PRISM model, with a suggested clinical utility of facilitating couples’ dialogue about their reasons for having sex (Beck & Robinson, 2015). The application of this exercise was studied as part of a brief (3.5 hour) couples’ workshop for improving sexual experiences after prostate cancer – in which couples completed the exercise together to clarify their sexual values (Hampton et al., 2013). During the workshop, couples were also provided information about behavioural strategies for adapting sexual activities (penetrative and non-penetrative) and ways of problem-solving around difficulties related to sexual function (e.g., scheduling sex, using lubrication, managing urinary leakage). In order to consolidate couples’ learning and assisting in goal setting, the workshop participants completed a commitment change statement, adapted from Lockyer et al. (2001). A total of 77 couples participated in the workshop, with an attrition rate of 24%; Hampton and colleagues (2013) suggested that the brevity and focus of the workshop facilitated higher participation rates. Change scores on the Sexual Function Questionnaire completed prior to and following the workshop revealed improvements for both patients and partners. Compared to waitlist controls, patients and partners experienced improvements with regard to the medical impact of the prostate cancer on sex while partners also demonstrated improvements in sexual interest, problems, and overall sexual function. At follow up, 2-months following the workshop, 32% of patients and 33% of partners reported that they had successfully implemented at least one of their goals from the commitment to change exercise. Barriers to change were mainly time

constraints/busy lifestyle and anxiety/stress or awkwardness. This study suggests that brief interventions that facilitate couple dialogue about sexual values by way of the PRISM model plotting exercise in combination with psychoeducation, behavioural change strategies, and goal setting are promising in promoting successful sexual adjustment after cancer.

### ***Enhancing Intimacy Through Sensate Focusing***

Following from the PRISM model, enhancing partners' valuing of sex for intimacy, in turn, bolsters their sexual resilience. As previously discussed, Reese et al. (2012, 2014) used sensate focusing in their intervention to enhance couples' sexual intimacy after CRC and was found to be one of the activities most used and rated most helpful and easy by participants in. The exercise of Sensate Focusing was developed by Masters and Johnson (1970) in order help partners to expand their approach to sexual activity while reducing the pressure of sexual performance. The first phase of Sensate Focusing involves taking turns in touching one's partner with a focus on one's own sensory experience and without the expectation of pleasure, arousal, or sexual intercourse (Weiner & Avery-Clark, 2014). The exercise is aimed at having the "toucher" explore their partner's body for their own self and interest, from a neutral, non-evaluative stance (Weiner & Avery-Clark, 2014). When engaging in this phase of sensate focusing, partners are to set aside an hour without distraction (e.g., children, pets, electronic devices) and remove as much of their clothing as they feel comfortable with (Weiner & Avery-Clark, 2014). The "toucher" then uses their fingers and hands to touch their partner from head to toe, front to back, avoiding typical erogenous zones (e.g., breasts, nipples, genitals); their focus is on the tactile sensation (i.e., temperature, texture, and pressure) (Weiner & Avery-Clark, 2014). If they find themselves becoming distracted (e.g., focusing on their partner's reactions, evaluating their pleasure, outside disturbances) they are to re-focus on the tactile sensation

(Weiner & Avery-Clark, 2014). The partner being touched, the “touchee”, is to focus on the tactile sensation on where they are being touched (e.g., temperature, texture, pressure) and to non-verbally communicate any discomfort to the toucher by moving their hand (Weiner & Avery-Clark, 2014). Partners then switch positions and repeat the exercise. Following this, both partners are encouraged to write down the sensations, any distractions, and whether they were able to re-focus on tactile sensation when distracted (Weiner & Avery-Clark, 2014). Subsequent steps in the first phase of sensate focusing include touching of breasts and genitals, mutual touching, partner astride, and insertion (Weiner & Avery-Clark, 2014). This phase of sensate focusing “serves as a means for diagnosing difficulties as well as practicing touching for one’s own interest, and this, in turn, systematically desensitizes participants’ anxiety and neutralizes their evaluating their experiences as successful or otherwise.” (Weiner & Avery-Clark, 2014, p. 316). Once partners have practiced the initial phase, a second phase of sensate focusing involves both verbal and non-verbal communication about touch and pleasure that encourages spontaneity, exploration and intimacy in touching (Weiner & Avery-Clark, 2014). Within the current intervention, sensate focusing is referred to as “mindful touching”, upon recommended by an expert in sexual health in prostate cancer, as being more accessible to patients and partners (J. Robinson, personal communication, May 31, 2018).

### **Intervention Protocol**

This two-session intervention adopts a systemic approach to the **process** of delivering content and facilitating couple dialogue. The therapist will encourage the couple to take a ‘participant-observer’ stance of their relationship throughout the course of the intervention to help couples make explicit their relational meaning system and underlying assumptions about their sexual and intimate relationship.

## Session 1

*Estimated length – 1.5 hrs*

The **purpose** of this session is to facilitate the couple's dialogue about their sexual and intimate relationship since the colorectal cancer diagnosis and treatment and the creation of the permanent ostomy (e.g., colostomy, ileostomy). The **goal** of this conversation is to have partners learn at least one new piece of information about themselves or their partner as it relates to their sexual and intimate relationship.

The **content** of session #1 will be 'divided' into four parts:

- (1) Current sexual and intimate concerns, from each partner's perspective
- (2) Couple strengths and ways of coping with changes to their sexual and intimate relationship
- (3) The results of the sexual values exercise of the PRISM model
- (4) Introduction to and planning of sensate focusing exercise

### ***Facilitating Couple's Dialogue About Sexual and Intimate Concerns (25 mins)***

Begin the session thanking the couple for completing the baseline measures and pre-treatment questionnaire; highlight the importance of the questionnaires in providing you with insight into how they are understanding/conceptualizing their current sexual/intimate concerns. Then ask the couple whether they have discussed their responses to the pre-treatment questionnaire and get a sense about how much the couple discusses the changes they have experienced since the cancer diagnosis and permanent ostomy.

*Have you spoken with each other about the pre-treatment questionnaire and your responses to some or all of the questions? [If yes, how was that conversation?]*

*Have you discussed these concerns with each other before? [If yes, how often and/or to what degree?] [If no, what has stopped you from discussing these concerns with each other?]*



Ask the patient to first describe the changes they have experienced in their sexual and intimate relationship since the cancer and permanent ostomy and get a sense of how sex/intimacy was before the cancer and ostomy. In turn, ask the partner to reflect on what the patient has shared.

*[Directed to patient] What changes have you experienced in your sexual and intimate relationship since your colorectal cancer treatment and ostomy surgery? How is this a change from your sex life and intimate relationship before the cancer and ostomy?*

*[Directed to partner] Would you agree with [partner]? How have you been impacted by these changes and in what way?*

*[Directed to both patient and partner] From both of your perspectives, how have these changes affected your relationship?*

Similarly, have the partner describe the changes that they have experience in their sexual and intimate relationship since the patient's cancer and permanent ostomy. In turn, ask the patient to reflect on what the partner has shared.

*[Directed to partner] Usually we think of the patient as going through changes as a result of the cancer and ostomy but there is a lot of research to suggest that partners can also experience a lot of changes. I'm wondering, from your perspective, what changes have you experienced in your sexual and intimate relationship since your partner's colorectal cancer treatment and ostomy surgery? How is this a change from your sex life and intimate relationship before your partner's cancer and ostomy?*

*[Directed to patient] Have you perceived these changes? How have you been impacted by these changes and in what way? Do you agree or disagree with the [partner]'s description?*

*[Directed to both patient and partner] From both of your perspectives, how have these changes affected your relationship?*

If any additional concerns were described by either patient or partner in the pre-treatment questionnaire but not yet discussed, raise the concern with the couple by asking if they have had any difficulties in that particular aspect of their sexual/intimate relationship.

For example: *Have you experienced any issues regarding initiating sex? Have you experienced any concerns with pain during intercourse since your treatment? Have you experienced any difficulties in getting an erection since getting your colostomy?*

As the couple discusses their concerns, provide education related to changes in sexual functioning and relational intimacy with a permanent ostomy following colorectal cancer, normalizing and validating their experiences whenever possible. Solicit feedback from couple after psychoeducation; confirm their understanding/explore their interpretation. Tell couple that they will also be provided with written educational information related to these changes.

Briefly summarize the current concerns that the couple has presented and solicit their feedback to confirm that you have understood each of their concerns. Keep in mind that partners can disagree on their concerns; highlight areas of agreement and disagreement in their individual conceptualizations of the changes they have experienced in their sexual and intimate relationship. Remind the couple that the purpose of the intervention is not necessarily to resolve these concerns but, instead, to help them to better understand their sexual and intimate relationship and become more aware of their existing relational strengths that they can use to better cope with their concerns.

***Couple strengths and ways of coping with changes to their sexual and intimate relationship (25 mins)***

Encourage the couples to become more aware of their ‘relational epistemology’ as it related to the sexual and intimate aspects of their relationship, both before and after the colorectal cancer and ostomy. Ask questions/make reflections to encourage couples to make explicit their implicit meaning systems and assumptions about their relationship.

*Can you describe to me what your sex life and intimate relationship was like before the surgeries and ostomy? When you did have sex in your relationship, how was it initiated? Who initiated it? How did it unfold from there?*

*In what ways is this similar or different to your sex life and intimate relationship now since the cancer and ostomy?*

*[If couple struggles with previous questions, can get more concrete/behavioural with the following questions] If I were a fly on the wall in your bedroom when you were having an intimate moment together or having sex, what would I see? Can you describe to me, kind of step-by-step, what a typical sexual encounter might look like for you?*

*When do you feel closest to your partner? What does he/she do or say that makes you feel connected?*

*How did you, as a couple, communicate about sex/intimacy before the colorectal cancer and/or ostomy? Has that changed in any way? How so?*

Encourage the couple to share, from their perspective, how they have coped with their difficulties to draw out their ‘relational wisdom’. Point out any examples of how the couple has exhibited qualities known to be enhancing of resiliency (e.g., acceptance, flexibility, persistence, empathy, mutual respect and vulnerability)

*I’m curious how you, as a couple, have been coping with the changes you’ve experienced to your sexual and intimate relationship [specify based on their unique situation].*

*How are [specify coping processes] working for you? [draw out helpful and unhelpful aspects]*

*When you experience a sexual encounter that doesn’t turn out as you expected or hoped, what do you do? How do you feel? What do you think?*

*[Engage couple in conversation about the meanings/assumptions they are ascribing to one another’s sexual expressions/expressions of affection or spurns to affection]*

*Do either of you have any ideas about what you might do in addition to what you’re already doing to cope with these changes?*

### ***Review the Couple’s Responses to the Sexual Values Exercise (25 mins)***

Remind the couple of the PRISM exercise

*As we’ve talked about, in our two sessions together, I’m hoping that you will both be able to learn more about each other when it comes to your sexual and intimate relationship. You might recall that in your pre-treatment questionnaires, I had you both rate how much you were motivated to have sex for the physical pleasure you get from sex and how much you were motivated to engage in sex for the intimacy or closeness you felt with your*

*partner when having sex. I then asked you to take a guess at how your partner would make the same ratings. I'd like us to talk about your responses to that exercise but first I'd like to give you a bit of background about why I had you do that.*

Briefly summarize the purpose of this exercise and the research that suggests that pleasure and intimacy/closeness are two of the primary motivators for engaging in sexual activity

*Research in this area has suggested that following cancer, couples engage in sexual activity for two primary reasons. One reason is for physical pleasure – so the enjoyment that they get out of the physical sensations of kissing, touching, oral sex and intercourse, with the ultimate goal being their orgasm from sex. The other reason for engaging in sex is for a feeling of intimacy or closeness with their partner – so this is the emotional connection that the partners felt while touching, kissing, and having sex. Of course, partners could be highly motivated by both of these reasons or might feel more motivated by one and less motivated by the other. The researchers found that partners reasons for engaging in sex could change over time and that partners in healthy relationships could differ in their reasons for wanting to engage in sex. The researchers came up with an exercise to help couples learn about what motivates each partner to have sex with the other and that is the exercise that I had you do in your pre-treatment questionnaires.*

Show the couple how the patient rated him/herself on both dimensions and have the patient explain their ratings. Then, show the couple the partner's guesses at how the patient would rate him/herself on both dimensions. Discuss the accuracy of the partner's ratings and have the partner explain their reasoning for making those particular ratings. Repeat this process as it relates to the partner's responses and the patient's guesses of the partner's ratings on each dimension.

Provide psychoeducation about resiliency and motivations for engaging in sexual activity with your partner. Have them reflect on these findings and their own values and experience when it comes to sexual motivations after cancer treatment and with the colostomy.

*We know from the research that if one or both partners place a high value on sex for physical pleasure and a low value on sex for intimacy, when they experienced a sexual encounter in which they didn't get the physical pleasure that they would have liked to have had – like reaching orgasm – they could be left feeling frustrated or disappointed and feeling as if future sexual encounters would turn out the same way. As a result they might be less interested or motivated to pursue sex again. On the other hand,*

*when one or both partners placed a high value on sex for intimacy, they felt that the encounter was satisfying and worthwhile because of the intimacy and closeness they felt with their partner. When these partners and couples experienced less physically pleasurable experiences, they were less likely to predict that future sexual encounters would turn out the same way. As it turns out, valuing sex for intimacy helped couples to stay motivated to engage in sex after cancer in spite of difficulties related to their physical functioning or experience. When they were motivated by both physical pleasure and intimacy, they were most likely to persist and be flexible in trying to find ways of adapting to or working with the changes they faced. What do you think of these findings? Does this resonate with your experiences at all?*

### ***Introduction to and planning of sensate focusing exercise (“mindful touching”) (15 mins)***

Describe Sensate Focusing and the rationale for having them complete the first stage of the exercise. If possible, get couple to plan when they would try out the exercise. Follow up session #1 with email with instructions for first sensate focusing exercise.

*Since we’ve talked about the benefits of valuing sex for intimacy, I’d like to propose an exercise that sometimes helps couples to appreciate touch and physical closeness with their partner for the intimacy it can bring them. It can be a helpful exercise for couples to try out as a way of getting physically close again after cancer, without the pressure of “performing” sexually. The purpose of this exercise is for you to engage in physical touch without the goal of having sex – in fact, sex is off the table in this exercise. In this exercise, you will take turns giving and receiving touch; for example [patient] could start first as the giver of touch, touching [partner’s] body for 20 minutes and once that time is up, you would switch roles and [partner] would touch [patient’s] body for 20 minutes. If you’d like to touch for longer, you could certainly do so but we ask you to aim for at least 20 minutes in each “role”. This exercise is about touching one another in a mindful way – what that means is that the focus of your thinking here is on the range of physical sensations and possibilities for touch; it’s about being curious about the other’s body, your own sensations as you touch your partner and your physical sensations as you are being touched. You can communicate throughout the exercise about how the touch feels but the goal is not to reach orgasm or to have sex, we want to reduce that pressure as much as possible. In this exercise, I’d like you to stay away from touching any erogenous zones; that means not touching genitals or nipples. If there’s anywhere else that is “off limits” for you personally you can also discuss and agree to those as a couple before you try out the exercise. You can be fully clothed, in underwear, or naked; that’s up to your comfort level but I do suggest eliminating all distractions and making sure the room is a comfortable temperature. You can even dim the lights, put on music, or light candles if that makes you feel more comfortable – whatever you like!*

*I will send you a document with more detailed instructions for the exercise but I'd like to first get your thoughts – how does that exercise sound to both of you? Do you have any questions or concerns about the exercise?*

*It's sometimes helpful – while we're together – to try out some “mindful touch”. Would you feel comfortable for example if [patient] were to try to “mindfully touch” [partner's] arm? [Have each partner in the couple try giving/receiving touch and have them reflect on the experience, encourage them to try out different pressures and rhythms of touch]*

*[If couple is receptive, plan time & problem-solve barriers] Do you know a day or time that might work for you to try out the exercise? Is there anything that might get in the way of your trying out the exercise?*

## **Session #2**

*Estimated length – 1.5 hrs*

The **purpose** of this session is to continue to facilitate the couple's dialogue about their sexual and intimate relationship since the colorectal cancer diagnosis and treatment and the creation of the permanent ostomy (e.g., colostomy, ileostomy). The **goal** of this conversation is to have partners consolidate their learning about themselves or their partner as it relates to their sexual and intimate relationship and set realistic expectations and goals for the future of their sexual and intimate relationship.

The **content** of session #2 will be ‘divided’ into three parts:

- (1) Couple's experience in completing the sensate focusing exercise
- (2) Reflection on their learning
- (3) Setting realistic goals for future

### ***Review the Couple's Experience with the Sensate Focusing Exercise (25 mins)***

Remind the couples of the exercise and the reason for completing it and ask them about whether or not they were able to try it out. Have them reflect on their experience. Highlight any learning and impact on their way of relating to each other intimately and/or sexually.

*Last time we were together, we discussed trying out “mindful touching”. Were you able to try out the “mindful touching” exercise? How did it go? What did you like or not like about the exercise? What was hard or easy about it?*

Encourage couples to take a participant-observer stance of their sexual and intimate relationship to draw out their “relational epistemology”, particularly with regard to how they typically relate intimately versus how the sensate focus exercise guided them to relate intimately

*Thinking now about how you typically relate to each other intimately or sexually [can recall specific examples from session #1], how was the mindful touch exercise different from how you typically relate? How was the mindful touch exercise similar?*

*Did it feel comfortable or uncomfortable? How so? Did this change as the exercise went on?*

*Were you able to communicate during or after the exercise about your experience? How did that communication go? If you didn’t communicate, what stopped you?*

*Did you learn anything about your intimate or sexual relationship from doing the exercise?*

*Moving forward, can you see yourselves making time for such an exercise? Why/why not?*

### ***Deepen and consolidate learning about sexual and intimate relationship (35 mins)***

Encourage couple to discuss what they learned about themselves, their partner, and their sexual and intimate relationship during the first session. Facilitate the couple’s continued dialogue about this learning while guiding the couple to take both participant and observer stance of their relationship. **Continue to draw out and highlight any relational strengths they describe that can be drawn upon for effectively coping** with the changes they have experienced in their sexual and intimate relationship. When appropriate, provide psychoeducation.

*We discussed a lot in the first session together, I'm wondering if you took anything away from that session? Did anything "stick out" to you from that session?*

*What did you learn about yourself from that session? What did you learn about your partner from that session? What did you learn about your relationship from that session? Your sexual/intimate relationship?*

### **Setting Realistic Goals For Future (30 mins)**

Encourage couple to start thinking about how they could apply their learning to the ways that they are coping with the sexual and intimate changes they have experienced.

*How can you use your learning [may specify what the couple described as new information/new learning] going forward in your process of coping with these changes?*

Complete the goal setting exercise

*It's often helpful to actually articulate some changes that you'd like to make. It's especially important when we do this to stay realistic in setting goals. If we don't make realistic expectations we can end up placing undo pressure on ourselves and feeling disappointed when we don't reach them. Setting goals together can be especially helpful because you can tap into your strengths as a couple and view the challenges you face as shared challenges to tackle as a team. How would you feel about coming up with three 'changes' or 'goals' you'd like to make together as a couple?*

*[Facilitate the couple writing down three goals or changes, may wish to integrate sensate focusing, if helpful can describe 'SMART' goals to help concretize goals (Specific, Measurable, Attainable, Realistic, Timeline)]*

*What might be helpful for you to make those changes? What might get in the way of making those changes?*

### **Debrief and Next Steps (5 mins)**

Thank couple for participating, allow them to ask any questions, and explain next steps (i.e., post-treatment questionnaire and 1-months and 3-month follow up).



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## Appendix C

### Commitment to Change Exercise<sup>1</sup>

As a result of your sessions, identify three concrete, measurable changes you will integrate into your sexual and/or intimate relationship. The intent of having you put this into writing is to allow you to reflect on what you have learned and where you would like to go from here in terms of your sexual and intimate relationship after colorectal cancer. This also helps us to review specific areas of impact that the sessions have had on your sexual and intimate relationship. During your post-treatment interview in one month from now, we would like to ask you whether these changes did in fact occur and if they didn't, what got in the way. This will be a way for us to assess the impact of our program. Thanks!

1.

2.

3.

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<sup>1</sup> Adapted from Lockyer, J. M., Fidler, H., Ward, R., Basson, R. J., Elliot, S., & Toews, J. (2001). Commitment to change statements: A way of understanding how participants use information and skills taught in an educational session. *The Journal of Continuing Education in the Health Professions*, 21, 82-89.

## Appendix D

### Intervention Satisfaction Questionnaire

We are asking for your assistance in providing feedback about the intervention for sexuality and intimacy with an ostomy that you recently completed. Your responses will be kept strictly confidential, and your name will not be associated with any of your comments.

#### **Program Evaluation:**

Overall, how satisfied were you with the online intervention for sexual and intimate adjustment (i.e., your two meetings with the therapist, the educational materials, and the exercise(s) that you completed/attempted between and during the meetings)?

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

Please elaborate:

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Overall, I found the intervention to be convenient:

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

Please elaborate:

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What did you like best about the intervention?

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What did you like least about the intervention?

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Did you learn anything from your experience in the intervention? If so, what was the most valuable thing you learned?

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Were there any components (e.g., couple exercises or written information) that you did not find informative or helpful? If so, please specify:

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

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The total amount of interaction with the therapist was sufficient.

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

Please elaborate:

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I found the online videoconferencing program easy to use:

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

Please elaborate:

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**Informational Section:**

Did you read the written educational material about sexuality and intimacy after cancer and when living with an ostomy?

- ☐ Yes, I read all of the written educational material
- ☐ Yes, I read some of the written educational material
- ☐ No, I did not read any of the written educational material

If yes, overall, how valuable was the information that you received from the written educational material?

1	2	3	4	5
No value at all	Little to no value	Some value	Quite a bit of value	Great deal of value

Please elaborate:

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How valuable was the mindful touch exercise?

1	2	3	4	5
No value at all	Little to no value	Some value	Quite a bit of value	Great deal of value

- ☐ Or check here if you did not attempt the mindful touch exercise

Please elaborate:

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How valuable were the two meetings with the therapist?

1	2	3	4	5
No value at all	Little to no value	Some value	Quite a bit of value	Great deal of value

Would you recommend the intervention to another couple facing changes in the sexual and intimate relationship while living with an ostomy after colorectal cancer?

☐ Yes      ☐ No

Please elaborate:

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**General:**

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

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

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Any additional comments about your experience(s) in the intervention?

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*Thank you very much for your feedback!*



## Appendix E

### Post-Treatment Semi-Structured Interview Protocol

#### Introductory Remarks:

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

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

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

#### **Please share with me your experience of the program/intervention**

- What was it like to take part in the two session intervention?
- What were your expectations going into the program? (probe re: whether these were met).
- In what ways was the program helpful to you? How so?
- Were there any parts of the program you found to be less helpful or unhelpful?
- What did you like most? What did you like least?
- What would you have liked more of? Less of?
- Is there anything about this program that you did not expect? Please specify.
- Please share what you felt was missing from the program. What would you have hoped to focus on more?
- What, if any, were the challenges to participating in the two sessions? [probe also re: logistical barriers]
- Do you feel better able to cope with the changes to your sexual and intimate relationship since participating in the intervention? How so?
- Please share with me your experience of the exercises completed in and between sessions
- Looking back, do you think the exercise on sexual motivations was a valuable exercise for you to complete? Why/Why not?
- Looking back, do you think the mindful touch exercise was a valuable exercise for you to try? Why/Why not?
- What, if any, were the challenges to completing the mindful touch exercise?
- In your second session, you made some promises to yourselves about changes or goals for your sexual and intimate relationship. Are those something you’ve kept in mind? To what degree do you feel that you’ve kept those promises to yourselves?

- What impact, if any, did these exercises have on your sexual or intimate relationship? Your overall relationship?

**Please share with me your experience with Molly McCarthy, your program facilitator**

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

**Please share with me your experiences of the online component?**

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

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

E.g., Did they have scheduling issues? Did they have difficulty completing the exercise between sessions? Did they have a problem ?

**Please share with me any other thoughts**

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

**Thank them once again for their participation and valuable feedback.**

## Appendix F

### Study Advertisement

Seeking research participants!  
Are you concerned about **sexual health and intimacy** while living with an **ostomy** after **colorectal** or **bladder** cancer?

#### An Internet Delivered Intervention for Re-Adjustment to Sexual Intimacy with an Ostomy After Cancer

##### Why an intervention for sexual health and intimacy after colorectal and bladder cancer?

Many couples struggle with changes in sexual health and intimacy caused by colorectal and bladder cancer treatments. Adjusting to these changes with an ostomy (i.e., colostomy, ileostomy, urostomy) can be even more challenging. Unfortunately, these issues are often not discussed with health care professionals and very few programs exist to help couples.

##### Why an online intervention?

Thanks to the ease and convenience of Internet communication, it is quickly becoming a popular way to deliver health care services. The intervention will be offered via secure and private online videoconferencing so that you can participate from the comfort of your home. By making use of online technology, this research has the ability to increase access of valuable services to colorectal and bladder cancer survivors across Ontario.

#### Interested in participating?

Principal Investigator is Dr. Karen Fergus,  
Sunnybrook Odette Cancer Centre.

To learn more about this study please contact the study coordinator, Molly McCarthy, at [REDACTED]@sunnybrook.ca or [REDACTED] ext. [REDACTED]

**Participating couples will receive a \$100 Amazon gift card!**

##### What is this research about?

The purpose of this research is to evaluate whether a two-session intervention that gives couples the chance to have facilitated conversations about the changes they have experience in their sexual health and intimate relationship can help enhance their ability to cope and adjust to the changes.

##### Who is eligible to participate?

- Individuals who have an ostomy (temporary or permanent) after colorectal and/or bladder cancer and are at least 1-month post active treatment
- Individuals who are in a committed relationship
- Couples with access to the Internet in a private space (webcams can be provided)
- Couples who currently reside in Ontario

##### What will participation involve?

Couples will be placed into one of two groups. The "intervention group" will receive the intervention immediately. The "information group" will receive written educational material only but can choose to receive the intervention after they complete the research. All couples will complete questionnaires about their sexual satisfaction, communication, and relationship at four times points over the course of 3 months. Couples in the "intervention group" will also give feedback in an interview.

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 **Sunnybrook**  
HEALTH SCIENCES CENTRE

Version date: 04/01/2019

## **Appendix G**

### **Healthcare Provider Semi-Structured Interview Protocol**

The following 60-minute interview is semi-structured and additional follow up questions will be asked as they arise during the interview. It will be audio-recorded.

#### **Part I: General experience addressing sexual health with patients**

What has your experience been in discussing sexual health with patients in your clinical practice?

Do you see these patients as needing support for sexual health?

Who typically broaches the subject? What are patients' typical reactions if you raise the topic of sexual health?

Do you address sexual health as a matter of course or on a case-by-case basis? How do you decide whether or not to address sexual health?

If you broach the topic, how do you typically do so? What kind of approach do you take? What kind of language do you use?

What are some challenges, from your experience, in discussing sexual health with patients?

How do you think you could improve on your inclusion of sexual health within your clinical practice, if at all? What kinds of support would you need? (probe re: common barriers ex: training, time, resources, private space)

#### **Part II: Insight into interventional research specifically**

Did you inform patients about the current project? If so, how did you present the project?

When did you decide to broach the subject?

How did patients typically respond?

How do you think recruitment could be improved? How do you think couples could be made to feel more inclined to participate?

Based on your clinical experience, why do you think we've had difficulty finding patients and partners to participate? (probe: for individual, systemic, and study/intervention design barriers)