

**“I-WE” BOUNDARY FLUCTUATIONS IN COUPLE ADJUSTMENT TO
COLORECTAL CANCER AND LIFE WITH A PERMANENT COLOSTOMY: A
QUALITATIVE VALIDATION STUDY**

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Abstract

This study aims to validate and further elucidate an existing classification system of couple adjustment to cancer, developed with breast and prostate cancer patients. The classification proposes that couples undergo shifts in their sense of togetherness (“We”-ness) and separateness (“I”-ness) during their cancer experience, which may either affirm or erode their mutual identity. The application of the “I” – “We” classification system to a different yet related population of couples coping with colorectal cancer (CRC) served as a novel approach to member checking as a means of validation. Nine patients treated for CRC and living with a permanent colostomy were interviewed alongside their well-partners and asked a series of open-ended questions in order to elicit information about their adjustment to the disease and appliance. Interview transcripts were coded in order to identify “I-We” shifts in couples’ adjustment, either as these were implicitly described within the couple’s dialogue about their experience, or as they were explicitly self-identified by the couple after they were presented with the “I-We” conceptualization of adjustment during the interview. With the exception of four “We”-eroding shifts, all of the 32 previously identified shifts within the “I-We” classification system were observed, some in unique ways given the specific needs and challenges of the CRC sample. Moreover, a new “I-We” process code was developed based on this analysis. Implications and future directions are discussed as they apply to colorectal cancer patients living with colostomies, and current theories of couple resilience emphasizing “We”-ness.

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"But let there be spaces in your togetherness and let the winds of the heavens dance between you. Love one another but make not a bond of love: let it rather be a moving sea between the shores of your souls" (Khalil Gibran)

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“I-We” Boundary Fluctuations in Couple Adjustment to Colorectal Cancer and Life with a Permanent Colostomy: A Qualitative Validation Study

Background on Colorectal Cancer and Colostomies

Colorectal cancer (CRC) is the third most diagnosed cancer in Canada (Canadian Cancer Society (CCS), 2014a). It is the second leading cause of death by cancer in Canadian men and the third leading cause of death by cancer in Canadian women. Oncologists develop individual treatment plans for CRC patients based on tumour site, stage, and type (i.e., colon versus rectal) that may include surgery, chemotherapy, and radiation (CCS, 2014b; Butler et al., 2013). When malignant tumours are located in the lower portion of the rectum, patients often undergo an abdominoperineal resection (APR), resulting in a permanent colostomy (Sprangers, Taal, Aaronson, & te Velde, 1995). While medical advancements have reduced the number of patients requiring permanent ostomies as part of their treatment (Butler et al., 2013), it is estimated that approximately 15% of patients diagnosed with colorectal cancer will need a permanent colostomy (Cancer Care Ontario, 2004).

Colostomies are required following sphincter-sacrificing procedures such as APRs in which a patient’s distal colon, rectum, and anal sphincter complex are removed and the anus sewn closed (Perry & Connaughton, 2007). A permanent colostomy is a procedure in which a portion of the large intestine is brought through the abdominal wall and secured to the skin surface (CCS, 2014c). The resultant opening is referred to as a stoma. Stomas resemble the interior lining of the mouth; they are soft, moist, and pinkish-red in appearance, containing many blood vessels. However, stomas lack the capacity for physical sensation, as they do not contain nerve endings. Patients living with permanent

colostomies wear a pouching system or appliance over the stoma in order to collect stool and gas from the gastrointestinal tract.

Quality of Life with a Permanent Colostomy

Given the invasive nature of the colostomy, it is not surprising that CRC patients with permanent colostomies report poorer quality of life than CRC patients living without permanent colostomies (Spranger et al., 1995). CRC patients with stomas experience concerns related to bowel function including increased bowel movements, diarrhea, actual or feared fecal leakage, and loss of control over waste and gas elimination (Burch, 2005; Nugent, Daniels, Stewart, Patankar, & Johnson, 1999; Spranger et al., 1995; Sun et al., 2013). Some patients may also develop parastomal hernias (Burch, 2005; Sun et al., 2013) or rashes on the skin surrounding the stoma (Nugent et al., 1999; Sun et al., 2013). These physical limitations may preclude the CRC patient from leaving his/her home (Spranger et al., 1995). Furthermore, to successfully care for their ostomy, patients must learn new psychomotor skills including cleaning the stoma and surrounding skin, changing their pouch, and disposing of their fecal output (Persson & Helstrom, 2002). These cleansing activities become a prominent part of patients' day-to-day routines and can be difficult to accomplish in public restrooms (Danielson, Soerensen, Burcharth, & Rosenberg, 2013; Sun et al., 2013). As part of managing the colostomy, patients may also change their diets including limiting foods that upset stoma functioning and odour, abstaining from eating before travel or special events, and altering the time and size of meals to control output (Nugent et al., 1999; Spranger et al., 1995; Sun et al., 2013).

In addition to the physical changes, the colostomy poses a myriad of psychosocial challenges. CRC patients living with permanent colostomies experience lowered self-

esteem and body image, embarrassment about their physical appearance, and heightened awareness regarding the visibility and odour of the pouching system in public (Burch, 2005; Danielson, Soerensen, Burcharth, & Rosenberg, 2013; Persson & Helstrom, 2002; Spranger et al., 1995). Patients with ostomies have reported an initial shock and heightened emotional distress at the first sight of the stoma (Danielson et al., 2013; Persson & Helstrom, 2002) and individuals can continue to experience altered body-image as long as 10 years post-surgery (Orbach & Tallent, 1965). As a result of the stigma imposed by the colostomy, patients may limit the types of activities and the amount of time spent outside of their home as a means of minimizing social discomfort (Danielson et al., 2013; Persson & Helstrom, 2002; Spranger et al., 1995). When travelling, individuals with colostomies are inconvenienced by practical considerations such as having to pack extra supplies and clothing as well as the potential inability to wear a seat belt due to irritation of the stoma (Sun et al., 2013).

A lowered sense of personal control was a significant psychological challenge identified in individuals adjusting to ostomies (McVey, Madill, & Fielding, 2001). Specifically, cancer patients with ostomies report feeling a lack of control over caring for the stoma, a dependency on health care professionals to learn about the stoma, and feelings of depression, especially during initial adjustment. Patients with stomas have described the experience as a sense of regression to infancy (Burch, 2005; Emslie et al., 2009). When possible, patients may employ colostomy irrigation, a mechanical method of flushing the bowels of stool by passing a solution through the stoma (Burch, 2005; Karadag, Montes, & Ayaz, 2005; Sun et al., 2013). In a sample of CRC patients adjusting to colostomies, irrigation took between 15-35 minutes to complete and aided patients in

gaining partial or full continence (Karadag, et al., 2005). With regular irrigation, patients can develop a more stable and predictable pattern of waste elimination and can opt to use stoma caps, instead of pouches, which are less cumbersome and visible under clothing. Importantly, patients who were able to irrigate reported significant improvements in their physical impairments, social functioning, mental health, and emotional distress (Karadag et al., 2005).

Physical damage, often permanent, caused by treatments for CRC as well as the colostomy itself pose changes to the sexual functioning of the patient (Sprunk & Altener, 2000). Men may report erectile dysfunction, inability to reach orgasm, and pain during intercourse (Nugent et al., 1999; Spranger et al., 1995; Sprunk & Altener, 2000). For men who engage in anal sex, removal of the rectum performed during colostomy surgery can represent the loss of a significant source of pleasure (Sprunk & Altener, 2000). Removal of the rectum in female patients can result in a shift of the vaginal wall and alter the angle of penetration during coitus. Women may report vaginal dryness, dyspareunia, and diminished orgasm (Burch, 2005; Nugent et al., 1999; Spranger et al., 1995). Shifts in uterus position as a result of ostomy surgery may lead to infertility, while the stoma may pose added challenges during pregnancy (i.e., bowel obstructions, lack of abdominal strength during labour) (Sprunk & Altener, 2000). In addition to the physical changes to sexuality, altered body image may also reduce an individual's desire for sexual activity (Cohen, 1991). Post-surgery, male CRC patients with stomas have reported a decreased desire for and pleasure in sexual activity (Spranger et al., 1995). Common concerns in engaging in sexual intercourse include

displacement of the appliance, damage to stoma, fecal leakage, and odour, noise, or appearance of the stoma (Cohen, 1991; Salter, 1992).

Cultural considerations are also important in assessing patient quality of life with the colostomy. In a sample of 178 Muslim patients receiving treatment for colorectal cancer, those who underwent an APR (versus sphincter-sparing resection or anterior resection) reported significantly poorer quality of life, pronounced changes to work and social life, and were more likely to discontinue engaging in religious practices such as prayer and fasting during Ramadan (Kuzu et al., 2002). Feelings of social isolation and loneliness were more common amongst those who stopped participating in their traditions. Although the reasons for abstaining from religious practices were unclear, the authors suggest that perceptions of uncleanness and the uncertainty about the validity of ablution when stool is eliminated involuntarily may contribute to the abandonment of prayer by Muslim patients with colostomies.

It is important to note that the quality of life of partners of individuals with stomas may also be affected. In a sample of 56 couples adjusting to permanent colostomies following treatment for colorectal cancer, spouses of the patients reported spending more time at home, reducing their social activities, ceasing or decreasing their sexual activity, and helping the patient care for the colostomy (Cakmak, Aylaz, & Kuzu, 2010). Sixty days after hospital discharge, partners of cancer patients with ostomies also reported higher distress than partners of cancer patients without ostomies (Oberst & Scott, 1988). Given their intimate relationship to the patient, it is important to consider how spouses' distress or anxieties around the ostomy may impact the dyadic relationship and the ostomy patient's coping. A partner who is overwhelmed or threatened by the presence of

the colostomy may in turn impede the coping of the patient by placing the patient in a predicament between managing his or her own worries as well as those of the distressed partner. Alternatively, spouses who are able to offer empathic and collaborative support to the patient, in spite of their personal reactions or fears regarding the ostomy, may help to bolster the coping efforts and adjustment of the patient. Given the impact of the ostomy on spouses, as well as the potential for rebound effects on the coping of the patient, it is clear that spouses should be included when studying quality of life and adjustment to living with a colostomy.

Dyadic Coping to Colorectal Cancer and Permanent Colostomy

The study of dyadic coping in relation to cancer has tended to focus on breast and prostate cancer patients and their spouses (Altschuler et al., 2009; Tuinstra et al., 2004). Despite identifying several significant challenges to patients and partners, little is known about *how* couples cope during the colorectal cancer experience, and more specifically their adjustment to the colostomy. It is particularly important to understand couples' adjustment to colostomies, as mental health concerns including depression, suicidality, and low self-esteem are more prevalent among CRC patients with stomas than among those without (Sprangers et al., 1995).

In a sample of 57 couples coping with CRC and a colostomy, spousal support was identified as vital to the adjustment of the patient, especially where the relationship between partner and patient was based on mutual affection (Sutherland, Orbach, Dyk, & Bard, 1952). However, where spousal relations were strained prior to the colostomy, they tended to worsen post-surgery. Couples who have strained sexual relationships prior to the colostomy were identified as particularly vulnerable to break down. In those couples

whose marriages endured post-surgery, well partners supported patients by helping them seek medical care, taking an active role in the care of the colostomy, minimizing their partners' concerns or fears, and prioritizing the needs of the patient (Dyk & Sutherland, 1956).

Partners' reactions to the physical changes posed by the colostomy are crucial to the patients' adaptation to the appliance (Dyk & Sutherland, 1956; Emslie et al., 2009). When patients feared rejection or disgust, or doubted their partner's ability to assist them, they were more likely to exclude the partner from their care (Dyk & Sutherland, 1956). Partners' reactions to the stoma can vary widely. Among 12 patients who underwent treatment for CRC and received a permanent colostomy, 75% of their spouses reported positive reactions (i.e., "I'm glad the cancer is gone," "It doesn't bother me") versus 25% who reported negative reactions to the colostomy (i.e., "Everything is bad about it," "It has an odour") (Northouse, Schafer, Tipton, & Metivier, 1999). In a more recent study, some partners refused involvement with the ostomy, viewing it as an intrusion and "foreign" object, while other partners became deeply involved in learning about and caring for the ostomy, viewing it as part of the patient (Ohlsson-Nevo, Andershed, Nilsson, & Anderzen-Carlsson, 2011). Research suggests that when partners have a strong sexual relationship with patients and are involved in patients' care prior to surgery, they are more likely to overcome their initial reactions of shock or disgust toward the ostomy and provide bodily care more freely to patients (Dyk & Sutherland, 1956).

A study of 22 female CRC patients with colostomies identified categories of supportive, unsupportive, and mixed supportive/unsupportive behaviours in male partners during adjustment (Altschuler et al., 2009). Spouses supported the female patients both

instrumentally (i.e., care of ostomy) and emotionally (i.e., assurances of normalcy and beauty, empathetic responses, concealment of worry). Patients identified emotional support as particularly beneficial to their adjustment. Conversely, partners had a negative impact on patients' adjustment when their behaviour was clearly unsupportive such as, withdrawal of care, reduced intimacy, and leaving the relationship. Some patients described their partners as feeling too burdened by their caregiver role, leading them to withdraw. Finally, some patients described a mixed type of support and withdrawal from their partners. These behaviours were characterized as only somewhat supportive, lacking sincerity, or given on a conditional basis. In line with previous findings (Sutherland et al., 1952), one patient described the colostomy as exacerbating the marital discord she had with her husband over their 26 years of marriage.

In a study of 13 couples adjusting to colorectal cancer, where 6 patients had received permanent ostomies, patients and partners were interviewed separately to assess their individual as well as dyadic coping (Ohlsson-Nevo et al., 2011). Some couples described the cancer experience as bringing them closer together given the threat of death to the patient. In such cases, couples found comfort in mutual exploration of existential concerns while others found strength in a silent togetherness. Additionally, patients struggled with the physical repercussions of their treatment (i.e., exhaustion, bowel disruptions, and pain), while partners took on added responsibilities including scheduling medical appointments and cleaning soiled linens. Many partners expressed feeling unprepared for these new demands; some feeling limited in their social activities or being forced into early retirement as a result. A shift in household and caregiving responsibilities falling on the shoulders of the well partner has also been reported in

previous studies (Dyk & Sutherland, 1956; Emslie et al., 2009; Northouse, Schafer, Tipton, & Metivier, 1999). In turn, CRC patients have expressed difficulty in surrendering former responsibilities or accepting personal caregiving from their partner (Emslie et al., 2009; Syke & Sutherland, 1956).

Given the impact of the CRC treatments and colostomies on sexual functioning, pleasure, and desire, it is important to understand how couples navigate their intimate and sexual relationships post-surgery. This experience seems to vary widely. Some couples are able to return to their pre-surgery sexual relationship, some describe having a different sexual relationship post-surgery, while others fail to resume any sexual relationship (Dyk & Sutherland, 1956; Emslie et al., 2009; Ohlsson-Nevo et al., 2011). When the sexual relationship was nonexistent post-surgery, some patients felt incomplete, while partners unanimously expressed an acceptance of this loss (Ohlsson-Nevo et al., 2011). In some cases, couples coped with sexual changes by developing alternative ways of expressing intimacy other than intercourse. In fact, male partners' continued intimacy was identified as a form of supportive behaviour to female CRC patients' adjustment to the ostomy (Emslie et al., 2009). Additionally, some partners believed that concerns of sexual functioning were personal to the patient and did not feel comfortable insisting that patients seek medical assistance to resolve or alleviate their sexual dysfunctions (Ohlsson-Nevo et al., 2011).

“We”-ness as a Form of Couple Resilience

Expanding the current discussion to include dyadic coping with cancer and illness more generally may help further illuminate ways in which couples adapt to colorectal cancer and a permanent colostomy. Within the literature of couple resilience exists a

concept termed “We”-ness. This refers to the collective identity of the couple, and a mutual receptivity and integration of the other’s perspective (Skerrett, 2010). In essence, couples create their own relationship culture, with its own ways of communicating and interacting (Fergus & Reid, 2001). It is important to understand that “We”-ness is not separate from the couple, but a complex, evolving, and often unconscious, process inherent to their relationship (Fergus & Reid, 2001; Reid & Ahmad, in press). Partners must re-define their individual identities to accommodate their role and identity within the relationship; the relationship itself is an emergent phenomenon of the partners’ always evolving, mutual identification (Reid & Ahmad, in press).

Couples’ dialogue of their relationship “stories” or their “relational epistemology” (Reid & Ahmad, in press) can help to make their “We” more explicit, bringing it into a conscious awareness (Fergus & Reid, 2001; Reid & Ahmad, in press; Skerrett, 2003, 2010). While speaking of their story, couples will spontaneously employ plural pronouns (i.e., “us,” “we,” “our”) (Fergus & Reid, 2001; Reid & Ahmad, in press; Skerrett, 2010). Reid and Ahmad (in press) suggest that this shift in language is indicative of the partners’ personal identification with the relationship. They also note that “We”-ness is distinct from other forms of social identification because its existence is dependent on the continued engagement between both individuals. When each partner’s self-identity is extended to the dyad, they have a vested interest in maintaining the relationship because it holds a personal value to the self. Therefore, they are more likely to behave in ways that support the relationship, including accommodating or accepting differences in the other and themselves, in order to maintain the survival of their symbiotic relationship. In

this way, “We”-ness can enrich and support both the relationship and the individuals that create it.

Research supports the notion that a couple’s sense of “We”-ness allows them to be resilient in the face of challenges, including illness. Based on in-depth interviews with 20 breast cancer patients and their partners, couple coping was categorized as either resilient or problematic (Skerrett, 1998). It was found that 85% of couples described as resilient adopted a shared ownership of the illness. Skerrett (in press) later proposed that a sense of “We”-ness promotes resilience because it encourages partners to take responsibility for their reciprocal influence within the relationship, safely share vulnerabilities, co-construct meaning of their experiences, adopt a positive outlook, and develop strong relational skills over time. In taking a “We” orientation, couples conceptualize the stressor as occurring to “us” and as a common responsibility to be tackled by the couple, thus leading them to engage in dyadic or “communal coping” (Lyons, 1998; Skerrett, in press). As couples have a more defined sense of “We”-ness, or a deep understanding of their relationship, they are more likely to develop and engage in dyadic coping patterns that are adaptive (Reid & Ahmad, in press; Skerrett, in press). “Positive dyadic coping” can in turn also strengthen couples’ sense of “We”-ness (Bodenmann, 2005).

As a result, therapeutic interventions for couples have been designed to bolster couples’ sense of “We”-ness. Reid, Doell, Dalton, and Ahmad (2008) report that couples’ “We”-ness following Systemic-Constructivist Couple Therapy correlate with measures of marital satisfaction, mutuality, closeness, and similarity, even two years following their treatment. Another therapeutic approach aimed at fostering individual and couple

resilience during illness specifically, helps couples to develop an awareness of their “We” identity and interdependence; encourages partners to share their individual illness stories in an effort to reduce blame and acknowledge differences; and teaches couples to nourish their sense of “We” through shared experiences and use it as a source of healing during their experience (Skerrett, 2003).

Recognizing the Role of “I” in Couple Resilience

While the literature suggests that couple resilience is strengthened through a fostering and awareness of “We”-ness (Kayser, Watson, & Andrade, 2007; Skerrett, 1998, in press), this appears to be an oversimplification of couples’ dynamic response and adjustment to illness (Fergus, Crump, Gaydukevych, & Male, 2012). Brennan (2001) suggests that couples’ adjustment to cancer is a turbulent experience that can rapidly change course as individuals within the relationship react to and cope with different stressors. As the adjustment to cancer is a variable process, it is conceivable that a couple’s sense of cohesion may be more accurately conceptualized as fluid, undergoing fluctuations between a sense of “We” and “I” as couples adapt to new challenges. While interviewing breast and prostate cancer patients and their spouses, couples’ fluctuations between a sense of “We” and “I” and vice versa were identified throughout their cancer experience (Fergus et al., 2012). These could be discrete instances or slowly evolving shifts that represent a change in the couple’s normative way of being through the erection or dissolution of a personal boundary by one or both partners, in order to accommodate the challenges posed by the illness (i.e., diagnosis, treatment effects, personal care, existential fears). Contrary to one’s expectations given the current literature on couple resilience which stresses “We”-ness, it was noted that shifts or boundary insertions

denoting a movement toward a greater sense of “I” or separateness in response to the cancer experience were not necessarily damaging to the couple’s maintenance of “We”-ness and in fact, could strengthen their collective identity and thus their resilience (Fergus et al., 2012). For instance, a partner who is attuned to and respecting of a patient’s emotional boundaries or need for personal space demonstrates understanding and love for the patient when he withdraws for a few days following hearing the news of his diagnosis (Fergus, 2011). In turn, the spouse’s acknowledgement, acceptance and care are stabilizing for the patient and strengthening of his identification with the relationship despite his withdrawal.

A paradigm for couple adjustment to cancer describing various “I-We” process codes (i.e., delineating types of fluctuations in togetherness or “We”-ness”, and separateness or “I”-ness) was developed by Fergus et al., (2012), and further refined preparatory to the present study in order to examine “I” and “We” shifts occurring in CRC patients and spouses and their effect on couple resilience (see Appendices A and D for a full description and organization of the “I-We” Classification of Couple Coping and Adjustment to Cancer). “I-We” processes that strengthen the couple’s sense of “We” are termed “We”-affirming processes, and are characterized by a ‘coming together’ or dissolution of a boundary between partners. For example, *Doing Everything We Can* in which partners band together to learn about the cancer and make treatment decisions as a team. In contrast, “I-We” processes that weaken the couples’ sense of “We” are termed “We”-eroding processes and are characterized by a distancing between partners, often due to a boundary being erected between self and other. For instance, *Dealing with It on My Own* in which the patient asserts autonomy at the behavioural/emotional level and

essentially shuts the partner out of the cancer experience. Finally, those “I-We” processes that have the potential to either strengthen or weaken the “We”, depending on partners’ individual reactions in response to the shift or boundary insertion/dissolution, are termed “We”-differentiating processes. An example of a “We”-differentiating process is *My Body, My Personal Space* in which the patient erects a boundary at the level of the body. In turn, the partner may feel shut out or rejected, ultimately leading this to be a “We”-eroding process. Alternatively, the partner may be respectful and accepting of the patient’s need for privacy/space, ultimately leading the shift to affirm the “We”. It is believed that couples may freely fluctuate between “We”-affirming, “We”-differentiating, and “We”-eroding processes in response to cancer related challenges. In other words, fluctuations are not unidirectional or sequential. The fluctuations between “I” and “We” are also classified more broadly according to the nature or theme of the challenge faced by the couple (i.e., existential fears, emotional burden of illness, physical or treatment concerns) (See Appendix A).

Current Study

The primary aim of the current study is to validate the “I-We” classification system (Fergus, McCarthy, Male & Crump, 2014) for couple adjustment to cancer, using a sample of couples adjusting to CRC and a permanent colostomy. The rationale for this novel approach to qualitative validation, using a different yet related population, is presented below in the Methodology section. This population was specifically chosen given the paucity of research in the area of dyadic coping to CRC and permanent colostomies. The literature that does exist often includes the single perspective of either the patient or the well partner, tends to focus more on the physical and practical

adjustments, and falls short of identifying patterns in couples' adjustment. Therefore, the secondary aim of the current study is to identify the unique challenges faced by CRC patients with stomas and their partners as well as the ways in which they adapt to or overcome these obstacles, with a particular emphasis on shifts between "I" and "We." Specifically, the current study addresses the following research questions:

- 1) Do couples adjusting to CRC and permanent colostomies experience similar shifts in their sense of "I" and "We," as demonstrated in couples adjusting to breast and prostate cancer?
- 2) Does the "I-We" conceptualization of couple adjustment to cancer, as developed with couples coping with breast and prostate cancer, resonate with couples adjusting to CRC and permanent colostomies? Can they identify specific instances or long-term shifts between a sense of "I" and "We" in their personal experiences with cancer and the permanent colostomy?
- 3) What are the unique challenges faced by CRC patients with permanent colostomies and their partners? Do these couples undergo any unique shifts between "I" and "We" during adjustment given their unique challenges?

Methodology

Despite the fact that quantitative and qualitative methods of inquiry are grounded in different epistemological assumptions and attempt to answer different types of questions (i.e., why versus how respectively), the value and rigour of their results are often compared to one another (Marecek, 2003). Quantitative analysis, based in positivism, is often regarded as objective, concrete, and scientific. In contrast, qualitative inquiry is cast as subjective, 'soft,' and unscientific. Most commonly, qualitative research

is criticized for an inadequate ability to generalize and skepticism over the validity or trustworthiness of data and the interpretations drawn from them (Lather, 1986; Marecek, 2003; Polit & Beck, 2010). As Creswell and Miller (2000) aptly point out, the available literature on qualitative validation is diverse, complex, and at times, utterly puzzling because of the varying conceptualizations, terminology, and approaches to validity.

Despite the varying perspectives, the consensus among most qualitative researchers is that there is a need to implement safeguards for enhancing analytic integrity (Creswell & Miller, 2000; Lather, 1986; Marecek, 2003). In recognition of the importance of credibility (Glaser & Strauss, 1967) or validity in qualitative research, the focus of the current study is to validate a new classification system for understanding couple adjustment to cancer based on partners' ongoing negotiation of self-other boundaries in relation to the stressor (Fergus, McCarthy, Male, & Crump, 2014). Patients and well-partners adjusting to CRC and a permanent colostomy were interviewed together. The interview consisted of two parts: (1) A dialogue about their cancer experience and general adjustment; and (2) an introduction of the conceptualization of "I-We" fluctuations in adjustment to cancer and an inquiry into whether or not couples could self-identify such shifts or boundary insertions/removals in their own experience.

As the principal investigator for this study, I employed different approaches to ascertaining the validity of the "I-We" classification of couple adjustment to cancer. First, interview transcripts from the present study were subjected to an analysis focused on gathering evidence that supported or disconfirmed the theory of adjustment; specifically, I reviewed the transcripts in order to identify which of the 32 types of "I-We" process codes within the classification system as reported by Fergus et al. (2012) were observable

in the CRC sample. This approach is consistent with Stiles' (1993) description of replication, in the sense that a previous interpretation was applied to new information. As is detailed in the analysis section below, my goal was to identify fluctuations that occurred in relation to "I"-ness versus "We"-ness over the course of partners' adjusting to CRC. Furthermore, I attempted to remain reflexive during the analysis (Creswell & Miller, 2000), acknowledging my predisposition for recognizing "I-We" process codes due to my previous involvement in refining the classification system. In other words, I proceeded carefully while coding "I" – "We" shifts aiming: (1) to be decisive and deliberate (i.e., not impulsive) in identifying "I-We" process codes, and (2) to not 'force' the data from the current investigation so as to fit with the existing "I-We" process codes outlined in the original classification system. Therefore, beyond acknowledging my own biases, I also remained open to adapting the existing framework based on new information and/or observations from the current dataset, a process Stiles (1993) terms "reflexive validity." When I found that an observed "I" – "We" shift in the current investigation did not fit the existing "I-We" process codes, I revised the classification system through the addition of a new "I-We" process code, a rearrangement of the existing "I-We" process codes, or the further refinement of the original "I-We" process code definitions. Thus the classification evolved in response to new observations. Lather (1986) also suggests that indicating how preexisting assumptions have changed as a result of new information contributes to the "construct validity" of a theory. The ways in which the classification system was expanded and adapted as a result of the current investigation will be presented in the Results section. Finally, in order to ensure the integrity of the current analysis, ongoing consultation with members of the Psychosocial

Oncology Lab at York University, and maintenance of an audit trail (i.e., memoing), were undertaken throughout the study (Creswell & Miller, 2000; Lincoln & Guba, 1985; Stiles, 1993).

In a further effort to validate the classification system, a methodology based largely on a transactional approach to validity was developed and then employed during the second part of the interview. A transactional approach to validity involves an interaction between the data, the researcher, and the participants with the goal of improving agreement and accuracy of interpretations (Cho & Trent, 2006). One form of transactional validity is known as ‘member checking’. This procedure involves taking the qualitative information and interpretations back to the participants to consult with them about their accuracy (Cho & Trent, 2006; Creswell & Miller, 2000; Lincoln & Guba, 1985). In this case, the participants are actively engaged in the validation process. Others have named procedures similar to member checking, “testimonial validity” (Stiles, 1993) and “face validity” (Lather, 1986). Regardless of the terminology, Lincoln and Guba (1985) identified member checking as essential to establishing credibility. Participants are encouraged to comment on whether the findings are accurate, logical, realistic, and legitimate and their feedback is subsequently integrated into the final report by the researcher (Creswell & Miller, 2000).

Kotre (1984) proposed three types of validating reactions during member checking: (1) participant expresses feelings of being understood; (2) participant has a reaction consistent with the interpretation; and (3) participant is spurred to provide new, meaningful information. Stiles (1993) warns, however, that researchers should not always

expect complete agreement from participants, due to lack of insight or unfamiliarity with the language and/or concepts in the interpretation.

It is important to note that the current study employed member checking in a novel way. Specifically, the conceptualization of adjustment concerning “I-We” boundary fluctuation and negotiation developed with previous couples adjusting to breast and prostate cancer, was presented to the current study participants, couples adjusting to CRC. Thus the participants had neither taken part in one of the original studies upon which the classification system was developed, nor did they have the same type of cancer as participants from the original analysis. The decision to conduct a member check with a new sample of CRC patients and their partners rather than the original sample of couples adjusting to breast and prostate cancer was borne from the idea that this novel method of member checking held the potential to validate the “I-We” conceptualization, while also expanding and enriching the original “I-We” process codes based on the unique challenges associated with couples coping with CRC, and provide an opportunity to learn about an understudied oncology population.

It can also be argued that replicating the classification system with a different yet related sample - that is patients and partners adjusting to a third type of cancer - is a form of triangulation. Triangulation is an approach to validation conducted by gathering information from multiple sources (i.e., participants, theories, methods) and assessing their agreement (Cho & Trent, 2006; Creswell & Miller, 2000). Couples adjusting to CRC as opposed to breast or prostate cancer, represent an additional data source with which the classification system may be replicated. Inclusion of multiple data sources reduces the likelihood of misinterpretation and convergence between multiple data

sources suggests stronger validity (Stiles, 1993). In other words, if couples adjusting to CRC are able to consciously identify with the concept of there being “I-We” fluctuations in relation to their own experience with cancer, or such shifts are implicit in their descriptions of their experience, such observations help to support the validity of the framework being investigated.

It is proposed herein that should the data support the validity of the classification system in a third cancer population, there would be preliminary evidence for the classification’s applicability for couples’ adjusting to other, if not all, types of cancer. This type of external validity is referred to as ‘analytic generalizability,’ evidence that a theory is supported across a variety of circumstances (Firestone, 1993). In the current study, such generalizability would entail a particular theory of dyadic coping with cancer evidenced across different cancer populations. Polit and Beck (2010) propose that generalizability in qualitative research can be enhanced through many avenues including the replication of studies and sampling, provision of rich descriptions, and the reflexivity and conceptual thinking by researchers. Many of these strategies were employed in the current investigation. Specifically, this study attempts, in part, to replicate the original study by Fergus, Crump, Gaydukevych, and Male (2012) by conducting in-depth semi-structured interviews with couples adjusting to cancer diagnosis and treatment. However, in the present case, the sample was drawn from couples adjusting to CRC as distinct from breast and prostate cancer. According to Firestone (1993), when results are replicated under different circumstances, there is stronger support for a theory and its generalizability. In other words, when patterns and relationships can be replicated across a range of individuals, the phenomenon described is robust and that, in turn, provides

increased reason to believe in the applicability and validity of the findings (Polit & Beck, 2010).

Finally, in offering a rich description of the current sample and the findings on couple coping and adjustment to CRC and living with a permanent ostomy, future readers of the current investigation will be afforded the opportunity to assess the transferability of the findings; in other words, the generalizability of the current findings to different populations or settings (i.e., couples adjusting to other types of cancer or non-oncological challenges) of which they are more familiar (Creswell & Miller, 2000; Firestone, 1993; Polit & Beck, 2010).

Method

Procedures

Participant recruitment. The proposal for this study was reviewed by the Research Ethics Board (REB) of Sunnybrook Health Sciences Centre and of York University, and approval was granted prior to commencing recruitment. The sample was collected in collaboration with the ostomy advanced practice nurse from the Odette Cancer Centre (OCC) at the Sunnybrook Health Sciences Centre. Eligible patient participants had received a diagnosis of CRC, underwent an abdominoperineal resection (APR), and had a permanent colostomy as a result of their treatment. Furthermore, in order to study dyadic adjustment from diagnosis to present, eligible patient participants were required to have begun their current relationship prior to their diagnosis and first course of active treatment. Recruitment was open to patients and partners aged 18-80 inclusive, with the ability to read and speak English. Couples could be heterosexual or same-sex, and did not need to be legally married.

Based on the eligibility criteria, prospective patient participants were contacted by the ostomy advanced practice nurse, who then inquired about their interest in participating in a study about couples' adjustment to CRC and a permanent colostomy. All efforts were made to approach prospective participants in a non-coercive manner and all were assured that their decision to participate would have no repercussions with respect to their current or future treatment at the Cancer Centre. In order to be least intrusive, prospective participants were contacted at least 3 to 6 months after the original surgery. I then contacted those who expressed interest in the study; confirming eligibility, providing them with details of the study objectives and procedures, and answering any questions. I conducted a similar conversation with the partners of prospective patient participants. When both prospective patient and partner participants were in agreement about participating, an interview with the couple was scheduled at their convenience. Participating couples had the choice of conducting the interview at the Cancer Centre or their home. Three elected to participate at the Cancer Centre and six were interviewed in their homes. Participants were not compensated for their time but were reimbursed for parking if the interview was conducted at the OCC.

While efforts were made to balance recruitment by patient gender, the majority of the final sample consisted of male patients ($n = 7$). Of the 21 prospective patient participants who were eligible and expressed a willingness to be contacted to learn more about the project, only 9 couples agreed to participate following their conversation with me. Five of the couples declined once contacted - three for privacy reasons, one due to illness of partner, and one for unspecified reasons. The remaining seven prospective

participants failed to return my voicemail messages. Of the 12 couples who declined or failed to connect with me, eight consisted of female patients and their partners.

Interview structure. At the time of the interview, patients and partners were taken through the informed consent process and invited to ask any questions (See Appendix E pg 99 for consent form). The participants were reminded of the time required to complete the study tasks, the purposes of the study, how the data may be used, and their right to refuse to answer any questions or discontinue their participation at any time, without consequence. The interviews were conducted with both patient and partner present. The interview was organized in two parts: The first part being a discussion of the couples' cancer experience and adjustment more generally; and the second part being an introduction of the "I-We" conceptualization and its applicability to their own experience of adjustment. The interview was semi-structured, consisting of open-ended questions designed to elicit information about the couples' experiences in adjusting to CRC and the permanent colostomy (see Appendix F pg 106 for interview protocol). The interview questions were carefully developed and then adapted in response to early interview findings in a way that was believed to best introduce the classification system and elicit participants' experiences of shifts between a sense of "I" and "We". The semi-structured format encouraged participants to share their experiences to the degree that they felt comfortable and allowed the investigator the freedom to pursue unanticipated avenues of interest relevant to the study objectives as they arose during the interview. The average length of interviews was 103 minutes (range: 71-119 mins) and all but two of the interviews were conducted by myself. Following the interview, both patients and partners completed basic demographic and treatment questionnaires (see Appendix G pg 109), and

general adjustment and relationship satisfaction questionnaires, described below. Patients and partners were then debriefed and thanked for the participation.

Materials

In addition to the interview, patients and partners were asked to individually complete a series of paper-and-pencil questionnaires (see Appendix H for patient questionnaires and Appendix I for partner questionnaires). These were administered as supplemental information to the interviews and are not part of the primary analysis. The following is a description of each questionnaire:

Kansas Marital Satisfaction Survey

This 3-item self-report measure was designed to quickly assess marital satisfaction (Schumm, Nichols, Schectman, & Grigsby, 1983). Respondents must rate their level of satisfaction with regards to their marriage/relationship, their relationship with their partner, and their spouse as a partner, using a 7-point scale (1 = extremely dissatisfied, 7 = extremely satisfied). Individual scores can range from 3-21, where higher scores indicate greater relationship satisfaction (Crane, Middleton, & Bean, 2000). Couple scores of satisfaction can also be calculated by averaging each partner's individual score. Crane and colleagues (2000) identified 17 as the cut-off score that distinguishes distressed from non-distressed couples. The scale has demonstrated high internal consistency (Schumm et al., 1983) and an adequate degree of concurrent validity with both the Dyadic Adjustment Scale and the Quality of Marriage Index (Schumm et al., 1986).

Revised Dyadic Adjustment Scale

The Revised Dyadic Adjustment Scale is a 14-item self-report questionnaire that assesses couple relationships across three categories; consensus, satisfaction, and cohesion (Busby, Crane, Larson, & Christensen, 1995). Respondents must rate each item using a 5 or 6-point scale. Total scores range from 0-69 with higher scores indicating greater relationship satisfaction. Score ranges vary within the categories of relationship dynamics; consensus (score range: 0-30), satisfaction (score range: 0-20), and cohesion (score range: 0-19). A cut off score of 48 is used to distinguish between couples described as distressed and non-distressed. The Revised Dyadic Adjustment Scale has demonstrated high reliability (Chronbach's $\alpha = .90$) as well as high construct and discriminant validities.

Illness Intrusiveness Scale

The Illness Intrusiveness Scale (Devins, et al., 1983) is a 13-item self-report questionnaire designed to gather information about the impact of illness on various aspects of patient functioning. Using a 7-point scale (1 = not very much, 7 = very much), respondents are to rate the severity of disruptions in various areas of their lives including health, work, recreation, finances, sexuality, and relationships resulting from the illness and/or its treatment. Total scores can range from 13-91, where higher scores indicate greater disruption by the illness. Evidence supports the validity and reliability of the scale (Devins, 1994). With permission from Devins (personal communication, January 15, 2013), the scale was also adapted for use with patient's partners in the current investigation.

Functional Assessment of Cancer Therapy – Colorectal (FACT-C)

The FACT-C is a self-report questionnaire designed to assess quality of life in CRC patients (Ward et al., 1999). The measure contains items related to concerns of the general cancer population as well as specific concerns unique to CRC patients. Concerns include physical, social, emotional, and functional well-being. Respondents rate their agreement to items on a 5-point scale (0 = not at all, 4 = very much) based on their experiences over the past week. The FACT-C has demonstrated good reliability and validity.

Analysis

The interviews were recorded and transcribed verbatim. N-vivo software was used to organize data and assist with managing the analysis. The goal of the analysis was to identify fluctuations that occur between respective partners' sense of "I" and "We", or vice versa, during their adjustment to CRC and the permanent colostomy in reference to the existing coding scheme. The analysis can therefore be partially described as a theoretical thematic analysis (Braun & Clark, 2006), as it was conducted with a theoretical lens focused on shifts between "I" and "We". In other words, the theoretical or deductive portion of the analysis entailed classifying the observed shifts using the "I-We" process codes. However, as opposed to making strictly deductive inferences, the current analysis also employed inductive reasoning in order to avoid forcing the data into the pre-existing classification system. Inductive reasoning in a thematic analysis consists of identifying themes as they appear in the data (Braun & Clark, 2006), and was employed in the current analysis as adapting and editing the "I-We" classification system based on new information from the current sample (i.e., addition of a new "I-We" process code, re-

organization of “I-We” process codes, edits to the “I-We” process code definitions and/or labels). In other words, the goal of the current analysis was not only to validate the “I-We” framework in CRC patients but also to refine the existing classification system and process codes in response to emerging data from the CRC patients and their partners. This type of action in response to new information is consistent with “reflexive validity”, in the sense that the investigator constantly moved between the interview data and the “I-We” process codes outlined in the original classification system (Appendix D) while remaining open to expanding or adapting the classification and process codes in response to new information emerging from the interviews (Stiles, 1993).

The analysis was a two-step process and a replication of the steps taken in the original study (Fergus et al., 2012). First, interviews were reviewed in order to identify portions of text for analysis. This was the first phase of the analysis and involved identifying passages of text from each transcript that were relevant to the study goals. A data extraction rule was developed based on whether the excerpt was considered ‘episodic’, ‘reflective’, or ‘linguistic’ in order to guide this process. The criteria defining each type of excerpt are as follows:

(1) *Episodic* excerpts refer to one or both partners describing a specific incident or event, anchored in space/time, during their cancer experience that was (a) salient for the couple and (b) considered relevant to the phenomenon of interest. For example, one female partner recalled being told that her husband was going to receive a colostomy:

All of a sudden you hear like ‘We’re going to remove the rectum and this bag is going to be there permanently’ and the way they explained in the beginning, it was very shocking. But as I said [the doctor’s nurse] really explained it to us, like

I said she spent maybe two or three hours just to explain it to us. (Couple 3, *Episodic; Riding the emotional rollercoaster*).

(2) *Reflective* data segments refer to portions of text where one or both partners described their adaptation to cancer and/or the colostomy in such a way that represented a shift between “I” and “We” or vice versa. These shifts occurred over time and are sometimes apparent to the couple only in hindsight. These are different from episodic excerpts in that they are more global, gradual, and abstract versus vivid and situated in a space/time. For example, one couple described a strengthening of their relationship in the following dialogue:

Female Partner: Ya, I think we came together, you know, slowly over time.

Like we’ve always been like we said together, but I think slowly over time things have, you know. And the further you get away from the surgery and the diagnosis, life like I said before becomes...

Male Patient: Life resumes [scoff/laugh]

Female Patient: Resumes. All but differently, a little bit, like I don’t think we could ever be the couple we were three years ago.

Male Partner: No, and I don’t want to be.

(Couple 2, *Reflective; A Journey Ending in “We”*)

(3) *Linguistic* data segments refer to when one or both partners, in speaking about their individual or shared experiences with cancer and/or the colostomy made a notable shift between individual and plural pronoun use or vice versa. For example, one caregiving partner discussed treatment changes, “So then he had to stop the chemo, so then we

started to worry again. Like, are we going to be okay? We don't have chemo going on any more, but we're okay." (Couple 6, female partner, *Linguistic; My Body, Our Battle*).

When more than one extraction criterion applied, it was noted that the excerpt reflected all applicable categories. The second step of the analysis entailed reviewing the episodic, reflective, and linguistic textual excerpts and coding them according to the relevant "I-We" process code(s) in the classification system (Appendix D). Where applicable, shifts were assigned more than one "I-We" process code (in the end, no more than three categories were assigned for any given interview excerpt). When new information emerged from the interview data with CRC patients and their partners, the original definitions of the "I-We" process codes were expanded or adapted accordingly. When shifts observed in the interview data with CRC patients and their partners could not be coded according to an existing "I-We" classification, a new "I-We" process code would be added to the classification. While the analysis was completed primarily by myself, ongoing consultation with supervising and peer-researchers was conducted in order to ensure the reliability and validity of the interpretations of data extracts, edits to existing classifications, and additions of new shifts.

Participants

The sample consisted of nine patients and their well-partners (N = 18) from the Greater Toronto Area (GTA). The average age of patient-participants (n = 9) was 60 years (range: 42-80 years). Seven of the patients were male and two were female. Patient-participants were diagnosed with rectal cancer, either primary (n = 6) or recurrent (n = 3), and on average were 57 years at time of diagnosis (range: 40-76 years). All patients underwent an APR, had a permanent colostomy, and received radiation and

chemotherapy as part of their treatment. The majority of patients identified themselves as White/Caucasian ($n = 7$), while the remaining two patients identified as Hispanic and East Indian. All patients were in heterosexual relationships with their partners. The average length of the relationships was 30 years (range: 4-55 years), and only one couple was unmarried and co-habiting. All other couples were married. The average age of participating partners ($n = 9$) was 57 years (range: 37-76 years). The majority of partners identified themselves as White/Caucasian ($n = 7$), while the remaining two were Asian and East Indian, respectively. The majority of couples ($n_c = 5$)¹ had children as a result of their current relationship. One patient had children from a former relationship. In most cases, the children were of adult age.

The majority of participants had some degree of post-secondary education, including some college/university ($n = 4$), a college degree ($n = 3$), an undergraduate degree ($n = 4$), a master's degree ($n = 1$), or a doctoral degree ($n = 2$). The remaining participants had high school ($n = 3$) or elementary school ($n = 1$) diplomas. More than half of the patients were not working, they were either retired ($n = 5$) or on disability ($n = 1$). The remaining three patients were employed full-time. Partners also reported variability across employment status; they were employed full-time ($n = 4$), self-employed ($n = 1$), or retired ($n = 4$).

Results from the Kansas Marital Satisfaction Survey revealed that both individual partners ($M = 20.50$, $SD = 1.15$, range = 18-21) and couples ($M = 20.50$, $SD = 1.06$, range = 18-21) were satisfied in their intimate relationship. As all of the couple scores were

¹ Note that n_c is used herein to denote number of *couples* while n is used to denote number of *individual* participants.

above the cut-off score of 17, all couples were characterized as non-distressed. Findings from the Revised Dyadic Adjustment Scale (R-DAS) indicated that partners reported mid to high levels of consensus ($M = 25.29$, $SD = 2.64$, range = 19-28), satisfaction ($M = 16.67$, $SD = 1.37$, range = 14-18), and cohesion ($M = 14.00$, $SD = 2.63$, range = 10-19). Total scores on the R-DAS were generally consistent with the Kansas Marital Satisfaction Survey in suggesting successful adjustment among couples ($M = 55.79$, $SD = 4.77$, range = 45-64). However, one patient's total score fell three points below the cut-off of 48, suggesting that this particular couple may be characterized as distressed. Unfortunately, consensus and total scores from four well-partners were excluded from the current analysis due to missing data (i.e. skipped items); this included the partner of the patient with the total R-DAS score that fell within the distressed range.

Total scores on the Illness Intrusiveness Rating Scale revealed that both patients ($M = 26.22$, $SD = 9.55$, range = 14-39) and partners ($M = 22.57$, $SD = 4.86$, range = 16-30) reported minimal to moderate disruption by the illness, possibly because the sample of patients had been living with the colostomy for 3 years on average. As two partners failed to complete the questionnaire, their results were excluded from the analysis. Review of the Functional Assessment of Cancer Therapy – Colorectal (FACT-C), revealed that patients' greatest concerns were in regard to the colostomy ($M = 20.12$, $SD = 2.90$), and functional ($M = 21.87$, $SD = 5.61$) and emotional ($M = 21.22$, $SD = 2.22$) well-being. Notably, their highest quality of life ratings were in relation to their physical ($M = 23.33$, $SD = 4.47$) and social/family-well being ($M = 26.56$, $SD = 1.81$).

Results

To varying degrees, all couples described fluctuations between a sense of “I” and “We” in their adjustment to CRC and the colostomy, either implicitly embedded within their discourse during the interview, or explicitly, as self-identified shifts when the couple was presented with the “I-We” conceptualization of couple adjustment to cancer.

Generally, these shifts were consistent with the processes listed in the original “I-We” classification system (Appendix D). All of the previously identified “We”-affirming and “We”-differentiating processes were identified in the interview content of this CRC sample, while not all “We”-eroding processes were observed². Appendix B presents the number of couples who described experiences consistent with each of the “I-We” processes, and Appendix C provides information about how the “I-We” processes manifested uniquely in the CRC sample (where this was the case), including illustrative quotes. The results begin with an overview of participant reactions to the “I-We” conceptualization of adjustment to cancer followed by a presentation of (1) the most commonly observed “I-We” processes, and (2) how certain processes were expressed in ways unique to coping with CRC and the colostomy.

Participant Reactions to “I-We” Conceptualization of Adjustment

While “I-We” process codes were identified in the discourse of all couples, participants had varying reactions when presented directly with the “I-We” conceptualization of dyadic adjustment to cancer. Just under half of the couples ($n_c=4$)

² The top two most commonly described shifts categorized as “We”-affirming, “We”-differentiating, and “We”-eroding, respectively are discussed in detail. Moreover, in order to contribute to the current knowledge of the challenges and needs of CRC patients and their partners, shifts that were manifested in a unique manner within the current sample are also discussed in detail. When applicable, an effort was made to choose interview excerpts that illustrated both the fluctuations between “I-We” as well as the unique experiences related to CRC and colostomies.

overtly agreed with the “I-We” conceptualization of adjustment and were able to clearly identify shifts within their cancer experience that were consistent with the notion that a couple’s sense of togetherness and separateness fluctuates over the course of adjusting to cancer. A third of the couples ($n_c = 3$) had a more mixed reaction toward the presented conceptualization of adjustment to cancer. Specifically, these couples were initially less eager to describe their experience as fluctuating between “I-We” because, while they often agreed that they became closer throughout the illness, they did not resonate with the notion of there being a boundary between themselves and the other, or requiring space from the other. However, following further discussion of the “I-We” conceptualization of adjustment, they were able to offer examples of instances that were characterized by a movement toward “I” and consistent with the “I-We” process codes, though they did not consciously identify them as such. Moreover, it was noted by couples in both groups that a mutual respect for one another’s individual needs and privacy was practiced prior to the cancer experience. In other words, this was not something “new” for the couples. When reflecting on the space they have granted one another over the course of their relationship, one male patient remarked, “You know and it’s refreshing and then she comes home I’m glad to see her, [...] truth to absence makes the heart grow fonder sometimes too, I mean it’s like a total example of us” (Couple 5).

Shifts explicitly identified by couples during this portion of the interview varied. A commonly reported shift for couples was a request for personal physical space or privacy around the colostomy and its related activities. Needs for emotional space following diagnosis, treatment, or a particularly stressful cancer-related event were also expressed. Others described a feeling of coping separately as one male patient described

feeling “in the same space but not connected” to his partner (Couple 2). Some couples discussed absorbing the news of diagnosis, exploring treatment options, and discussing existential fears together. One patient described individually pursuing alternative treatments, against the wishes of his spouse, as he was resistant to receiving the colostomy. Couples also recalled times when they found comfort through being near one another or touching, or times when they were so in tune with one another that they knew what the other was thinking without saying a word. The redistribution of the patient’s responsibilities to the partner, both practical and physical, was also a shift identified by several couples. While couples agreed with the conceptualization of their adjustment as a fluctuation between “I” and “We,” they also stated that the experience solidified their sense of togetherness.

Two of the nine couples were more hesitant to describe their experience as consistent with the “I-We” conceptualization of adjustment. These couples denied feeling a need for separateness during their experience. They characterized their experience as having a stable sense of “We”-ness or togetherness throughout the diagnosis and treatment trajectory including living with the ostomy. In these cases, proposing the “I-We” conceptualization of adjustment led couples to reveal “We”-affirming processes, for example their ways of communicating around the stoma or a new appreciation for their relationship.

“We”-Affirming Processes

“I-We” processes categorized as “We”-affirming ultimately work to create or strengthen a sense of “We”-ness with the couple. These processes were most often characterized by a ‘coming together’ of partners surrounding a cancer related issue, or by

a prioritizing of one partner within the couple for long-term benefit and survival of the “We”.

Doing everything we can ($n_c = 9$). This type of “I-We” process represents the partners uniting in their efforts to tackle the cancer. This can include learning about the cancer, exploring various treatment avenues, and jointly making treatment decisions. Essentially, couples are taking a “We”-orientation to the cancer and perceiving it as “our” problem to solve. This approach was often reflected in their use of plural pronouns – particularly when the caregiver spoke of the illness in “We” terms given the disease was technically the domain of the patient. For instance, when describing their dyadic coping, one female partner commented, “We have a chance, we are fighting for [it]. We are not waiting for the time to come, we are going to stay here to the end, to the positive end, just to get out from this one, right?” (Couple 7, male partner, *Reflective; Doing Everything We Can*).

In specific reference to the CRC and colostomy sample, this shift was apparent in the ways that couples researched colostomy functions and appliances together. Some couples expressed hearing the word “colostomy” or “stoma” for the first time as they were told that the patient would be receiving one as a permanent consequence of their treatment. Consequently, learning about how to manage and care for the colostomy, discovering their preferred pouching system amongst the myriad of products available, and establishing a reliable relationship with a supply vendor could prove to be a lengthy process for the couple. One partner recalled the couple’s first experiences in learning about the colostomy and its supplies:

We got pamphlets, and yeah. I went a little bit on the Internet and looked a little bit, but that's not nice. You find too many things you don't even want to know [laughs]. But in the beginning it was not easy because you have so many things, when you wanted to order that stuff. So many things to choose from that you go 'oh my God' and in the beginning you even order the wrong things. But now we know. (Couple 8, female partner, *Episodic; Doing Everything We Can*).

Additionally, it emerged in this sample that in some instances partners took on the role of advocate or speaker for the patient in relation to their treatment. These shifts entailed the well-partner, or healthy "I" fighting for the appropriate treatment of the patient, or more vulnerable "I". One male patient recalled his wife advocating for him following a misunderstanding with medical staff:

Using her managerial skills [partner] told them, 'look it – you guys are supposed to let us know what's happening so we can do [it]. We were supposed to be here at two o'clock to get the pick line done.' [Partner] gave them heck, told them that we weren't leaving until the pick line is in. (Couple 6, *Episodic; Doing Everything We Can*).

Collaborative caretaking ($n_c = 9$). *Collaborative Caretaking* entails couples collectively taking responsibility for tending to the patient's often deeply private physical needs³. Despite these often being moments of particular vulnerability for the patient, the

³ *Collaborative Caretaking* was formerly subsumed under *Doing Everything We Can*. However, upon reviewing the interview excerpts coded as *Doing Everything We Can*, it was noted that numerous excerpts were related to joint caretaking patients' physical needs. It was also observed that a collective orientation toward physical care of the patient was distinct from joint decision-making or learning around the cancer/colostomy in that it was exhibited through the *physical* 'coming together' of patient and partner in an effort to fight the CRC and adapt to the colostomy. Due to the frequency and distinct characteristics of the excerpts related to physical care, the "I-We" process code of *Collaborative Caretaking* was created. It was categorized as a "We"-affirming process in the theme of *Managing the Illness*, as it represents a shift toward "We"-ness as the couple navigates the demands of the CRC and colostomy.

couple makes a natural shift toward the inclusion of the partner in the patient's physical care. This tendency speaks to the deep level of comfort between partners, as one male patient explained, "we know each other inside and out anyways, so what's the difference?" (Couple 4; *Reflective; Collaborative Caretaking*). In this regard, patients often express a gratitude for the acceptance and generosity bestowed by their partners. One patient was particularly appreciative of his partner's willingness to be involved in his physical care, "Thank God for my wife... She has been okay with me, so I don't have a problem. Sometimes if you give a cold shoulder then you would feel that, but she hasn't." (Couple 3, male patient, *Reflective; Collaborative Caretaking*).

In the current sample of CRC patients with colostomies, partners' degree of involvement in caring for the colostomy varied from direct care of the colostomy (i.e., changing pouching system, assisting in irrigation): "[Male patient] has had his colostomy for what, how many years? Five years, honey? [turning to male patient] He did his first colostomy change by himself when he went with our son out west this summer," (Couple 6, female partner, *Episodic/Reflective; Collaborative Caretaking*), to indirect care of the colostomy (i.e. purchasing ostomy supplies, monitoring foods that disrupt or help the functioning of the colostomy, checking in about characteristics of stoma output, cleaning soiled linens):

Oh my gosh, I mean there is output, there is no output, the colour of the output, oh my gosh. And there is gas and there is no gas, and there is pain and there is no pain, and I have two [obstructions] and I was dying in pain, which I resolved both at home with his help. (Couple 7, female patient, *Episodic; Collaborative Caretaking*).

Certainly, physical caretaking for the patient could also be burdensome for the well-partner who could experience a sense of restriction based on the need to be near to the patient in the event of physical care needs. Having been responsible for the majority of her ill-partner's direct care needs, one well-partner noted her renewed sense of freedom when he became more physically independent:

So even him, like now for five or six months, I can say like we don't have to worry about being with each other all the time. Like he can take care of himself, except changing the phalange, he knows whenever it's time he will tell me. But other things he can manage on his own, so that's the good part, like you have the freedom and also the peace of mind that if he's alone or going to the public washrooms or things where you cannot just go with him, then he can manage the things on his own. (Couple 3, Female Partner, *Reflective; Collaborative Caretaking*).

It is important to note that while *Collaborative Caretaking* may be burdensome, it was also motivated by a deep emotional attachment between partners and the simple desire to be helpful and supportive, not necessarily due to physical limitations imposed on the patient by the appliance, "I think [patient] is happy having me do [the colostomy changes]. It's no problem for me to do it for him and it lasts for 7 or 8 days so we're very lucky that way too." (Couple 6, female partner, *Reflective; Collaborative Caretaking*).

My body, our battle ($n_c = 8$). This "I-We" process entails couples taking collective ownership of the cancer itself. It is characterized by partners' expressing themselves in a way that conveys that *both* the patient and well-partner were undergoing and experiencing the illness at its various stages (i.e., diagnosis, chemotherapy, surgery)

and is most often apparent in the couple's use of "We" language. One participant, for example, remarked, "...and then we start doing chemotherapy for 4 months." (Couple 7, female patient, *Linguistic; My Body, Our Battle*). These types of statements suggesting a collective experiencing of treatment are common amongst both patients and partners in their description of the cancer experience.

This "I-We" shift was also uniquely expressed within the CRC sample through references to the ill partner's body and adjustment to the colostomy, as though it was the couple's shared body. When describing a couple's routine in caring for the stoma, one patient recalled, "early on we had a rash, quite a severe one, we even took pictures of it" (Couple 6, male patient, *Linguistic; My Body, Our Battle*). In reality the rash was restricted on a physical level to the skin of the patient, however, the language use points to the collective experiencing and sharing of the physical burden of the colostomy. Additionally, physically speaking, only patients have to adjust their diet in response to the colostomy; however, many partners also described undergoing this change. One patient remarked, "our diet has changed, much to the disagreement of our children." (Couple 2, male patient, *Linguistic; My Body, Our Battle*). This particular manifestation of *My Body, Our Battle* illustrates that this "I-We" process can be consciously undertaken by the couple, presumably in an effort to support the patient by sharing in lifestyle changes in response to the patient's bodily adjustments and physical needs.

Accepting changes and losses together ($n_c = 8$). This process pertains to the couple's shared experiencing of cancer-related losses and changes. Most often, this entails changes to their sexual intimacy as a result of losses or changes in sexual functioning of the patient. However, it may also entail the couples' surrendering of a

meaningful aspect of their lifestyle or identity. Within the CRC sample, adjustments to the sexual functionality of the patient were common. Specifically, many couples discussed finding alternative sexual activities. Following his treatment for CRC, one male patient had difficulty gaining and maintaining an erection and as a result, the couple struggled with intercourse. As they describe, they found alternative ways of being intimate:

Male patient: Well it's not intercourse like it used to be. It's more, like I said, it's mainly masturbation.

Female partner: Yeah. Well it's oral sex more than anything. (Couple 6,

Reflective; Accepting Change and Losses Together)

Another female patient struggled with intercourse as she experienced pain during penetration. She and her husband experimented with using a vibrator, which also caused her pain. She described her anxiety toward penetration and the sexual activity which works for them, "I'd be like, oh you know, 'Oh here we go, we've got to do it now' and you know. So now we – we've almost come back to the way we were before we were married [laughs]. We just rub." (Couple 1, female patient, *Episodic/Reflective; Accepting Changes and Losses Together*).

Preserving the "I" identity of the other ($n_c = 7$). This "I-We" process relates to the well-partners' efforts to support the dignity of the patients and not draw attention to the losses, damages, or disabilities imposed by the illness. This includes partners' efforts to maintain normalcy; working towards minimizing change in the patients' routines, abilities, and sense of self, especially a sense of self that has been altered by the illness. Within the CRC sample, this shift was manifested in the partners' efforts to re-assure the

normalcy of the patients' physical appearance. As part of *Accepting Changes and Losses Together*, one female patient purchased ostomy-specific apparel in the hopes of attractively covering her stoma while engaging sexually with her partner. However, her partner's reaction to her efforts to cover her stoma, helped instead to re-assure her of her physical attractiveness in his eyes. Together, they described this interaction:

Female patient: But I got on the Internet right away and I found this website called Ostomy Secrets. So it's like Victoria Secrets, ya know [...] they also showed a "vixen belt" that you could wear for when you're having sex [...] It was the prettiest little lace belt that I ordered right away. You know with visions that we, you know... [laughs]

Male partner: So here's the deal, here's the deal. So the first time here's the thing, it's like "Ya, ya that's cool" whatever and all that. So then about like the [third] time and whatever. And then it's like...

Patient: Don't even wear it!

(Couple 1, *Episodic; Accepting Changes/Losses Together & Preserving the "I" Identity of the Other*)

Partners of CRC patients also made efforts to help them restore a more positive post-stoma body image as well as re-establish their regular routines and activities. One partner recounted purchasing a belt for her ill-partner which allowed him to play tennis:

I mean he likes to play tennis, but sometimes with the colostomy it's not that easy [...] I found on the internet a belt, a nice belt, but they just have that in the US. [...] But we just could order that in the US and we did that and through the internet and, yeah. That helps because it, you know, it's a little bit, yeah. It gives

him more security because he does not have always to worry about what happens if that thing brakes or whatever, so it is a little bit more protected and it moves a little bit more, you know, the whole back to the sides (so it is more). Makes it better. Looks also better, right. (Couple 8, female partner, *Episodic; Preserving the “I” Identity of Other*).

Finally, other partners helped patients maintain their dignity in public settings.

One partner monitored when the stoma output could be smelt. As she explained:

All of our friends and family know, I think [...] it’s just when it gets smelly, eh? Sometimes I say honey I think it’s time to change it or something like that, but I just worry for the other people. (Couple 6, female partner, *Episodic; Preserving the “I” Identity of Other*)

Another partner acted as a trusted ‘second eye’ about the visibility of the colostomy pouch before the couple left the house. The patient in this couple remarked, “I’ll put something on and I’ll go ‘Can you see my bag?’ or ‘Can you see the – ’ especially in a bathing suit, right?” (Couple 1, female patient, *Episodic; Preserving the “I” Identity of Other*).

Finding a shared language ($n_c = 6$). This “I-We” process entails the couples’ process of developing an idiosyncratic way of communicating about cancer and its related struggles. Within the current CRC sample, this change in communication manifested itself in a number of ways. In an effort to bring levity to an otherwise somber experience, many couples used humour as part of their regular interaction. One partner who formerly worked as an emergency medical services professional, learned to use humour in the workplace, a coping skill which he described applying to the cancer

experience with his ill-partner: “It would be the worst [...] and I’d like say something silly like ‘Rectum/Wrecked ‘em? Darn near killed ‘em!’ And then we’d laugh [...] if you’re not laughing, you’re crying. (Couple 1, male partner, *Episodic; Finding A Shared Language*). Couples adjusting to CRC and colostomies also developed ways of speaking about colostomy related activities. One partner described the couple’s dialogue around irrigation, “Well when we talk I say, ‘Are you doing your thing?’ That’s what we call it.” (Couple 1, male partner, *Episodic; Finding A Shared Language*). Another remarkable and particularly common way in which couples developed a language around the colostomy was by naming the stoma or appliance. One partner stated, “We’ve named him, Bob” (Couple 2, female partner, *Linguistic/Episodic*) while another revealed, “Her name is Bertha [...] crazy Bertha.” (Couple 7, female patient, *Reflective*). By personifying the stoma, it becomes a third entity within the relationship. Moreover, naming the device allows the couple to covertly discuss it in public free from fear of embarrassment.

Safeguarding our little secret (n_c = 5). Couples efforts to cope with the cancer privately are captured in *Safeguarding Our Little Secret*. This process involves couples establishing a parameter between themselves and the outside world; privately and without fear of judgment, partners can express their concerns, especially in relation to aspects of the cancer that are shameful or embarrassing for one or both partners. Within the CRC sample, it was found that couples also discuss if, when, and how they will disclose the CRC diagnosis or the resultant permanent colostomy to people outside of the relationship. One partner recalled a short time the couple spent away from friends and family after being told of the diagnosis:

We stopped in [city] to just kind of talk things over, we stayed a couple of days and that was pretty emotional for us [...] and we hadn't told our kids, we hadn't told our friends, like we just kept it all to ours and you know because they'd already been through a lot with the other deaths that [had gone on] in the summer so we didn't want to trouble them until we knew what was going on [...] good place to collect our own thoughts and have our cries and get emotional and then face the music. (Couple 6, female partner, *Episodic, Safeguarding Our Little Secret*)

Some couples decided not to disclose widely the CRC treatments and colostomy to those outside of the relationship. As one partner explained, "We didn't go around announcing that they removed her rectum, and this is what happens and this is what you have to do and all that" (Couple 1, male patient, *Episodic; Safeguarding Our Little Secret*). For other couples, the decision to disclose the CRC and colostomy to their family and friends was more straightforward. One partner recounted the conversation she had with her ill-spouse about disclosing the colostomy, "I just asked him, he went to the choir at that time, and I said 'Are you going to talk about it?' And 'Yeah, sure, let's talk about it,' and that was it." (Couple 4, female partner, *Episodic; Safeguarding Our Little Secret*). Additionally, some couples felt that disclosing the presence of the colostomy to others could ameliorate certain situations, as one partner explained, "If somebody is just visiting or if we're visiting somebody, he will explain. Like we went for the adoption classes, we had four days there, so the first day he explained to people who were sitting around the table that this is the problem, I may pass gas, and this is the reason." (Couple 3, female partner, *Episodic; Safeguarding Our Little Secret*).

“We”-Differentiating Processes

“I-We” process codes categorized as “We”-differentiating are those which hold the potential to either affirm or erode the “We” depending on how partners react or respond to the shift. Generally, when partners are able to undergo a differentiating process without it threatening their identification with the relationship, the shift ultimately affirms the “We”. In contrast, when partners react to “I-We” differentiation with feelings of rejection or disconnection from their partner, the shift is more likely to erode the “We”.

My body, my personal space ($n_c = 7$). This process occurs when the ill-partner erects an “I” boundary clearly distinguishing the “I” from the “We” at the level of the body, explicitly or indirectly. This shift may be momentary or last for several days/weeks. Explicit shifts within the current sample often pertained to requests for privacy during irrigation or caretaking of the colostomy. One well-partner remarked on a subtle but real change in restroom etiquette between her and her partner:

So there’s that boundary now that when he’s doing that – the irrigation– I would never barge in. Whereas if he was, before, having a bowel movement on the toilet, I wouldn’t barge in necessarily but I wouldn’t feel so – it wouldn’t cross my mind that he’s embarrassed that I’m there. (Couple 2, female partner, *Reflective; My Body, My Personal Space*).

Partners were typically understanding and respectful of this request for privacy in relation to the colostomy. One partner commented, “When he changes, he does not want me to be around, so that’s fine. I accept that.” (Couple 8, female partner, *Reflective; My Body, My Personal Space & Granting Space/Autonomy*). Partners’ respect of their ill-partners’

request for physical space due to bodily changes was a unique manifestation of *Granting Space/Autonomy* within the CRC sample.

Explicit representations of *My Body, My Personal Space* included reminders to the partner that the CRC was contained within the body of the patient. One patient described feeling frustrated and unheard by those around her, including her partner, when discussing her medical concerns, and in response asserted her role as patient:

... then [I] say, ‘who is the patient? You or me? Who is suffering?’ ‘No because I know how you feel.’ No you don’t. Which is the thing that everybody goes, ‘No I know how you feel.’ No you don’t. Did you have my cancer? (Couple 7, female patient, *Episodic; My Body, My Personal Space*).

Indirect demonstrations of *My Body, My Personal Space* within the CRC sample occurred when the patient hid or covered the stoma in the presence of their partner. One partner described a moment that occurred a few days prior to the interview in which her ill-partner hid his stoma after getting out of the shower, “you didn’t have the bag on so you just, you can see the stoma, and you kind of cover it up and I was just standing there and I was like ‘You don’t have to do that.’” (Couple 2, female partner, *Episodic; My Body, My Personal Space*). Another patient remarked, “to me it’s like my body was perfect before, like it was. Now it’s this thing is [...] I’ll let her see me with the bag hanging off it but that’s about it, I won’t let her see my stoma” (Couple 5, male patient, *Reflective; My Body, My Personal Space*). Some partners felt shut out or isolated during these moments, in response to her ill-partner covering his stoma, one partner revealed,

I think, what bothers me is that he’s self-conscious around me about it and I wish he wasn’t. Cause, I mean, we’ve been together, married, for 16 years and I’ve had

two children and he's witnessed that. I mean, you know, that's about as intimate as you can be, like, and I – it doesn't bother me at all. (Couple 2, female partner, *Reflective; My Body, My Personal Space*).

Meanwhile another partner admitted to never having seen the stoma and feeling comfortable with that physical separation from her partner, “[I’ve] never seen the actual [stoma] ... it’s always like this, the bag hanging there every time I see it.” (Couple 5, female partner, *Reflective; My Body, My Personal Space*).

Suffering under the surface ($n_c = 5$). This shift applies to partners as they prioritize the patient by silencing their own emotional reactions. This is motivated by a desire to protect the vulnerable patient and appear, at least on the surface, as a strong and stable source of support. Within the current sample this shift most often occurred at the time of diagnosis, as one partner described:

I remember being in the room with [doctor] and feeling like I had to, feeling like – cause I could have fallen apart, but I didn't and just I think, you got sad, and I think I remember thinking, ‘oh this is my moment,’ I don't mean like that but this is my time to be the stronger one and not to fall apart right now. I did, later. But, um, many times. (Couple 2, female partner, *Episodic: Suffering Under the Surface*).

A new demonstration of this “I-We” process also emerged from the current interviews. Specifically, partners reported speaking with other family and friends in an effort to relieve their emotional needs without burdening the patient. One partner off-loaded emotionally onto her ill-partner, until he alerted her that her fears/worries were scaring him. She recalled, “So that’s when I thought, you have lots of friends to talk to,

so you know I'd be talking to them and they were all extremely supportive, all of our friends, which helped a lot." (Couple 6, female partner, *Episodic, Suffering Under the Surface*). In some couples, the patient was aware of the partner's efforts to appear strong, "and I know that he goes and cries with my daughter, and my son, and all the friends and all the stuff, but then he comes with me and he tries to be the hero [...] I really appreciate that." (Couple 7, female patient, *Reflective; Suffering Under the Surface*).

Keeping this to myself ($n_c = 3$). This boundary insertion occurs when well-partners experience thoughts or feelings which are considered inappropriate or unacceptable and therefore do not share them within the dyadic discourse⁴. Within the CRC sample, this process was uniquely manifested as disgust toward the colostomy. One partner, described her initial thoughts toward the colostomy:

I think the operation, before the operation I'm really worried. You know it was like, oh my God, he's going to have that thing and I didn't I at first didn't even know what it is, [...] and oh 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 and that [...] (Couple 5, female partner, *Episodic; Keeping This to Myself*).

At the time of interview, this particular partner had yet to see her ill-partner's stoma, partially because he always wore his colostomy pouch in front of her, and partially because of her own discomfort with the stoma.

⁴ This "I-We" process code was formerly named *Feeling/Thinking the Unspeakable*. In this sample, some partners did not explicitly state that they withheld the information but it was assumed that there was a time in the cancer experience that it was not expressed. The codes's name was changed as a result of this observation.

“We”-Eroding Processes

“We”-eroding processes include “I-We” processes that create a felt sense of separateness between partners. These shifts work to breakdown the “We” by creating tension, disconnection, and isolation between the two “I”s of the couple.

Clash in coping styles ($n_c = 5$). Shifts entailing a *Clash in Coping Styles* were described by approximately half of couples. In these cases, partners were coping in opposing fashions, creating tension in their sense of “We”. Couples reflected on these shifts as times when they felt disconnected. One partner described this feeling during the couple’s early experiences with CRC, “When he was first diagnosed sometimes I felt like we were in our separate worlds because we were coping differently with it.” (Couple 2, female partner, *Episodic/Reflective; Clash in Coping Styles*). This partner was particularly anxious about her husband’s well-being and this came through in her consistent requests for updates on his condition and her reminders to him to take care of himself:

Obviously when you’re going through it, there is a lot of stress and anxiety and emotions and you know sometimes we would butt heads. I worry a lot, I’m a worrier so I would be worried a lot of the time and [patient] doesn’t worry. So during those – during the whole treatment and surgery, I probably spent a lot of time worrying and I think that bothered him because I was constantly asking after him. (Couple 2, female partner, *Reflective; Clash in Coping Styles*).

The partner was correct in her perception of the patient, as he described feeling burdened by her requests and comments:

You know they do those linear pain scales [...], 0 being nothing and 10 being the worst you've ever experienced. I was consistently like a 6 for six months. And typically when you're, like [partner] says, asking after someone if there isn't progress, what I sort of got frustrated with is that I almost feel like I'm letting you down by not saying 'Yes things are better.' Because you want to be able to say 'You know what? It's better today! It's good, it's good.' (Couple 2, male patient, *Reflective; Clash in Coping Styles*).

Also in response to anxious comments from a partner, another patient felt she had to assert an emotional boundary between she and her partner. The partner recalled, "he said to me, 'Will you stop? You're scaring me,' I said 'Well I guess I am over-reacting,' [...] and I think that was a turning point for us." (Couple 6, female patient, *Episodic; Clash in Coping Styles*)

Another couple clashed as a result of their worldview, the partner being a believer in a higher power, he said:

I get myself, you know in those situations, I sometimes look on the sky in the night, the stars, and I'm trying to get, to understand that at the end of the day, it doesn't matter what you do, there is a will from somebody else who may take over your wish and it will happen. So you try to, myself try to accept whatever will come up, okay. (Couple 7, male partner *Reflective, Clash in Coping Style*).

In contrast, the patient in this couple was much more of a realist:

[Partner] puts everything on religion, I don't. You know that you always say that there's a bigger plan, blah blah blah, and I always say okay so if God has this plan for me, he's not very friendly. But it's how it is and there is, again, no sense in my

opinion to dwell over things I cannot change. And it's not good as an antidote to face cancer with a sense of "why me? Why me?" (Couple 7, female patient, *Reflective; Clash in Coping Style*).

This particular couple also disagreed over the information they wanted to receive from the medical professionals. The partner wanted concrete answers and probabilities of treatment success so that he could plan, while the patient felt that this information had no bearing on the outcome of her treatment. She recalled, "I remember once he asked in what grade is the cancer, and I say, 'no don't tell him in my presence. If you like to know, go outside, because I will fight this, that's [not] a matter if one or five.'" (Couple 7, female patient, *Episodic; Clash in Coping Styles*).

Misalignment around care decisions ($n_c = 2$). Partners' disagreement surrounding the appropriate course of treatment is at the core of this "I-We" process. While this shift was expressed only in a minority of couples in the current CRC sample, its occurrence points to the struggle some patients have in relation to accepting and pursuing CRC treatment that will result in a permanent colostomy. In the current sample, one patient was very resistant to the concept of having a colostomy as a result of his treatment, feeling it was an affront to his sense of self and personal identity as a healthy, vital man. He wanted to explore alternative methods of treatment, stating:

I wanted to experiment with it; I felt I still had time. Like when they were talking about – the doctors – about the cancers and it was explained to me different cancers have different personalities and that I'd actually had this for a long time and it took a long time to get where it was and I felt that I had time to try different

things (Couple 5, Male patient, *Reflective/Episodic; Misalignment Around Care Decisions*)

Meanwhile his partner felt disappointed given the potential risks of delaying recommended treatment. She explained:

I don't agree with him looking for like natural thing... I feel like no, he's wasting his time and this cancer is not going to wait it's gonna just, you know, spread because it's already on the – we were told it's stage two (Couple 5, *Reflective/Episodic; Misalignment Around Care Decisions*)

Eventually a discussion with his son helped him to overcome his “vanity” and opt for treatment including the colostomy. In the second case, the patient decided that he wanted to enjoy the remainder of his natural life without opting for CRC treatment and the colostomy. Not until he recognized the toll this decision took on his wife, did he decide to pursue treatment:

Oh no no, [partner] is incredible. If it was not because of the incredible woman I have with me, I will have even [opt] from the very beginning, where my [initial] plan, I didn't know how things, I was completely [...] “well if I have a couple of months left I'm going to enjoy the time.” And then I was thinking of going on a cruise. We went on a cruise, yeah. And yeah travel a little bit of that, but when I saw the way she was suffering because of [it], I decided okay I will put all my [...], and after that it was easy. You make a decision, yeah. What else you can do? (Couple 8, male patient, *Reflective/Episodic; Misalignment Around Care Decisions*).

Newly Identified “I-We” Process Code

Illness as a wedge between us ($n_c = 2$). In addition to confirming many of the original “I-We” process codes in the classification, new information gained from interviewing CRC patients and their partners provided grounds for adding one other code that had not previously been captured – *Illness as a Wedge Between Us*⁵. This shift speaks to a physical boundary being erected between the couple as a result of the cancer treatment, precluding them from sharing in the same experience. The colostomy imposed a physical barrier within the CRC sample. Specifically, one couple was unable to enjoy swimming together on their vacation, as the patient recounted:

We went on a vacation when the kids were at camp, we went away to Montebello and it was like 40 degrees like this and sitting by the pool wearing a t-shirt like I [did] when I’m outside now and you’re swimming and I’m watching you swim. I wasn’t allowed (Couple 2, male patient, *Episodic; Illness as a Wedge Between Us*).

In another case, a couple could not share the same bed for the fear of the patient getting injured - a particularly difficult adjustment as described by the partner:

It was difficult [laughs]. My habit was, like I could not, I was not able to sleep, unless I really get close to him, otherwise I wasn’t able to sleep. So that was the difficult part for me, to stay away from him, not to hurt him or not to kick him or do anything like, I had the habit of kicking him or banging into him (Couple 3, female partner, *Reflective; Illness as a Wedge Between Us*).

⁵ This “I-We” process code was categorized as a “We”-differentiating process having the potential to either erode or affirm the “We” depending on the partners’ reaction to the shift. It is organized under the theme *Managing the Illness*.

This sense of forced separation due to the physical limitations of the illness/colostomy can cause feelings of loss and frustration in partners, as their usual ways of being close and sharing activities are disrupted. This process code has the potential of eroding the “We”, should the loss consume or further separate partners. If, instead, partners accept the loss together, perhaps by recognizing the potential for more dire consequences (i.e., death of patient), then this shift can lead to an affirmation of the “We”.

Revisions, Additions, and Expansions of Remaining “I-We” Process Codes

In keeping with reflexive validity, a number of the descriptions or definitions of “I-We” process codes were expanded and edited in response to the new interview data with CRC patients. Generally these changes were nuanced; reflecting the unique adjustment experiences of couples to CRC and colostomies, and bore minimal impact on the overall “I-We” classification system. The detailed changes, including illustrative quotes, are presented in Appendix C. When applicable, quotes were chosen to reflect both the shift and its unique manifestation in the current CRC sample.

Discussion

The current investigation aimed to validate an existing classification of couple adjustment to cancer entailing fluctuations between couples’ sense of “I” and “We.” After interviewing couples about their experiences coping with CRC and life with a permanent colostomy, transcripts were analyzed to identify shifts between “I” and “We” that were consistent with the pre-existing classification system. Additionally, a novel approach to member checking was employed by presenting the conceptualization of “I-We” adjustment to the CRC couples, and inquiring about whether they could relate to the

described adjustment dynamics, and/or identify these such shifts or self-other boundary insertions/removals in their own experience.

Results from the current analysis are generally supportive of the validity of the pre-existing “I-We” classification of couple adjustment to cancer. In addition to confirming the majority of the already identified “I-We” process codes in the CRC and colostomy sample, the current analysis uncovered a novel “I-We” process code and helped to expand and enrich the descriptions of the original process codes. Support for the “I-We” classification system within the CRC and colostomy sample also provides preliminary evidence for the analytic generalizability of the framework. In other words, this particular theory of couple adjustment to cancer is evident in other oncological populations. Moreover, the current investigation helped to broaden current knowledge on dyadic coping to CRC and colostomies; revealing the unique ways in which the “I-We” processes manifested in this understudied cancer population.

On a broad level, the current investigation helps to validate the proposed pattern of couple adjustment underlying the “I-We” classification system, that is, couples’ experiences of fluctuations between togetherness and separateness in their adjustment to cancer. “I-We” codes like *Doing Everything We Can* illustrate couples’ ability to ‘come together’ and take collective responsibility of the illness, while other codes such as *My Body*, *My Personal Space*, and *Keeping This to Myself* demonstrate instances when partners move toward separateness and/or assert a need for independence and autonomy during their adjustment. These fluctuations between “I” and “We” in sharing and experiencing the illness are consistent with Baxter’s (1990) interpersonal relationship contradictions; autonomy—connection, openness—closedness, and predictability—

novelty. Baxter outlined six reactions that couples have in response to these contradictions. One such response is *reframing*, in which partners do not view the contradictions as constituting opposites but complements. For example, autonomy is not the opposite of connection, but instead can serve to bolster a couple's connection. In Baxter's sample of undergraduate students, *reframing* was rare, particularly at the beginning stages of relationships, but was found to enhance relationship satisfaction, especially in response to the autonomy—connectedness contradiction. She proposed, therefore, that *reframing* may be more common amongst partners in long term relationships, such as marriage. The current investigation of largely married couples, may illustrate *reframing* of contradictions during adjustment. For example, partners' respect of patients' requests for emotional and/or physical space, as displayed in *Granting Other Space and Autonomy*, may point to their ability to *reframe* the request for separateness as an opportunity to enhance the couple's connection. In other words, partners' positive and supportive reactions toward "We"-differentiating processes (i.e. *My Body, My Personal Space*), help to ensure the shift ultimately affirms rather than erodes the "We".

An examination of individual "I-We" codes comprising the classification system sheds light on the unique challenges faced by CRC patients with colostomies and their partners. A striking manifestation of *My Body, Our Battle* in the current investigation came through in couples' use of plural pronouns when discussing the bodily consequences of the CRC treatment and the colostomy. In particular, partners' use of "We" language suggested that they too were undergoing the CRC treatments and experiencing the bodily repercussions of the colostomy, even though the disease itself was physically contained within the patient. This observation was consistent with Fergus'

(2011) conceptualization of adjustment to cancer as a shared, embodied experience between partners of a couple. Of particular relevance to the current discussion, she found that partners of patients coping with prostate cancer expressed physically feeling as if they too were undergoing the ill-partners' cancer treatment. For example, one wife recalled dreaming that she was undergoing her husband's surgery. These experiences suggest that couples share a figurative communal body, in which physical damage to one individual results in damage to the other. Fergus went on to propose that this communal body developed as a consequence of the partners' shared connection and the well-partner's deep empathy for the patient. Partners' ability to emotionally and psychologically "feel for" the patient transcended to a physical level. In the context of the current investigation, Fergus's findings suggest that *My Body, Our Battle* not only affirms the couples' sense of "We"-ness but perhaps also the communal body they share.

However, as Fergus (2011) describes, the illness also acts as a constant reminder that the couple is in fact comprised of two separate bodies and that the physical demands, whether temporary or permanent, are ultimately born only by the ill-partner. This sense of forced separateness manifested itself uniquely in the current sample as *Illness as a Wedge Between Us* in which the physical demands of the CRC treatment or colostomy precluded couples from engaging in formerly shared activities, such as swimming together or sleeping in the same bed. Couples must not only grapple with existential fears of separation as in *Our Life Without Me* and the *Insidiousness of Cancer*, but they must also cope with involuntary separation in the here-and-now.

As a result of the physical consequences of the CRC, all but one couple also underwent changes in their intimate relationship. As part of *Accepting Changes and*

Losses Together many couples described finding alternative sexual activities or new ways of intimately interacting with one another. In their presentation of The Physical Pleasure - Relational Intimacy Model of Sexual Motivation (PRISM), Beck and Robinson (in press) propose that a couples' sexual resilience in response to sexual dysfunction and/or decreased sexual desires stems from their ability to value sex for its relational intimacy versus physical pleasure. They found that in response to the sexual challenges imposed by prostate cancer, couples who were motivated to engage in sexual activity out of a desire for emotional closeness and connection, were more likely to accept their current situation, exhibit flexibility in their perceptions of what constituted sexual activity, and persist in their efforts to find a solution to the sexual changes (Beck, Robinson, & Carlson, 2013). In extending this model of sexual adjustment to the current findings, it is possible that the CRC and colostomy couples who were able to accept the changes to their sexual relationship and find alternative means of expressing their intimacy were able to do so because they valued sex for its relational intimacy. Given that the majority of couples in the current investigation discussed facing sexual changes, PRISM may be of use in helping CRC patients with colostomies and their partners adjust sexually following treatment.

Finding a Shared Language was expressed in this sample by patients and partners developing ways of communicating around the colostomy. Couples used humour to ease CRC and colostomy related stress, developed unique terms or language around colostomy related activities such as irrigation and, remarkably, even named the appliance. In a study of patient adjustment to CRC and colostomies, Sun et al. (2003) reported that a well-adjusted patient had named her appliance, "sweet pea". The current investigation

expanded Sun and colleagues' finding by demonstrating that this process is also adaptive within the context of the *couple*. Together, patients and partners name the appliance and develop a language around it; in sharing this process they are able to covertly communicate about the stoma in public. Moreover, the couple's process of naming the device and finding a shared language around the stoma is a reflection of their unique identity and way of communicating with one another (Fergus & Reid, 2001). This languaging allows the couple to define and control the ways in which they integrate the appliance into their relationship and lives. For example, the use of stoma-related humour is a reflection of the couples' ability to ease tension around the device, ensuring that not all of their conversations about the appliance are heavy or shameful. At the same time, in naming the appliance couples personify it; treating it as its own separate entity, apart from the patient and the dyad. In other words, through this use of language, partners draw a line between themselves and the stoma. In objectifying the stressor, the couple precludes the negative impacts of the illness from defining their shared identity, allowing them to engage their dyadic coping to overcome the stressor, and ultimately strengthen their sense of "We" (Fergus, in press).

In addition to communicating with *one another* about the stoma, couples must also negotiate discussion of the stoma with outside others. As observed in *Safeguarding Our Little Secret*, partners made decisions together about whether or not to disclose the presence of the colostomy to their family, friends, and even strangers. In a study of men with prostate cancer and their wives, most men chose not to disclose their diagnosis when possible (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000). One reason given for not disclosing was the potential for stigmatization, namely fear of ridicule due to the sexual

side affects of the disease. Given the very sensitive nature of the stoma function and its associated challenges (i.e., odour, noise due to gas, visibility under clothing, restriction in activities), CRC patients with colostomies arguably face even greater potential for stigmatization. Therefore, it is of little surprise that some couples in the current study chose not to make public the patient's stoma. Interestingly, other couples found that disclosure was beneficial in circumstances when the smell or noise of the stoma was unavoidable and obvious to others. In either case, couples' sense of "We" was acting as a buffer around their shame and embarrassment toward the stoma. Together they could share in their fears surrounding the stoma and decide if, how, where and when to disclose; neither partner was alone. Additionally, partners' efforts to uphold the dignity of patients in *Preserving the "I" Identity of Other* illustrate how the "We" worked to reduce the potential stigma surrounding the stoma.

Despite couples' efforts to engage their collective resources in tackling the illness, a *Clash in Coping Styles* was discussed by many of the partners. This failure to cope in tandem occurred when partners' individual coping efforts conflicted with or undermined the others'. In these cases, couples' coping could be conceptualized as incongruent or oppositional (Revenson, 2003). Partners under stress are bound to engage in their individual default coping strategies, and when these strategies differ or conflict, partners may hold on to their preferred way of coping and want their partner to follow suit (Reid, personal communication, July 11, 2014). Partners who continue to cope individually and in opposition to one another may feel a great sense of tension and frustration within the relationship. Instead, successfully coping with illness is believed to involve partners using similar coping strategies by which neither impede the other, or complementary

coping strategies in which each partner's coping efforts 'fit' with and strengthen the coping effort of the other (Revenson, 2003). Reid and Ahmad (in press) describe couples' coping as a "We" as an emergent phenomenon of the partners' individual coping systems. When couples undergo challenges together, they strengthen their mutual understanding, empathy, and interpersonal processing, allowing them to better cope as a dyad, which in turn, enhances their "We"-ness or identification with the relationship.

A common manifestation of *Clash in Coping Styles* in the current sample was observed when well-partners' attempts to provide support actually resulted in overwhelming the patient, raising feelings of anxiety and failure. Coyne, Wortman, and Lehman (1998) described this type tension between partners during adjustment to major life changes (i.e., illness, career change) in their model of *Miscarried Helping*. Initially, patients and partner view the illness as "our" problem, essentially taking a "We" orientation and a shared responsibility over the illness. However, as time passes, well-partners become burdened by these responsibilities; feeling anxious about their partners' progress (or lack there of), exhausted by role changes, and alone in their efforts to cope. Patients in turn may feel uncomfortable in receiving care from their partner and troubled by their lack of autonomy and independence. If this situation persists, both partners feel trapped. Well-partners may become increasingly frustrated and resentful of their role while patients feel guilty when they cannot report improvements in their condition, leading some to act the part instead. As one patient in the current sample conveyed, he felt like he was disappointing his partner when he could not report progress in his pain levels.

The well-partners may also construe the situation as surmountable if only the patient would make the necessary effort. Therefore, they begin to monitor and offer advice to the patient, which can in fact undermine the intrinsic motivation of the patients' coping efforts (Coyne et al., 1998). In the current sample, constant monitoring and excessive worrying on behalf of the partner were common causes of tension within the dyad, especially when that worry frustrated and/or overwhelmed the patient. If the patient does not (or cannot) heed the given advice, the well-partner may feel that the patient is rejecting their support. Moreover, because the well-partner has taken on a shared responsibility of the illness, he/she feels personally attacked when the patient does not make progress. Meanwhile, the patient, experiencing no improvement in their condition and a continued intrusiveness by their partner, may feel hopelessness and a loss of control. Coyne and colleagues (1998) outline how, in an effort to regain self-control, patients may overtly reject their well-partners' advice. This may lead the well-partner to exhibit hostility toward the patient which may in turn lead to the patient pushing away from the partner. Framed within the context of the "I-We" classification, the model of *Miscarried Helping* offers an illustration of how couples' initial efforts to cope as a "We" can shift to conflicts between the two "I"s in response to the overwhelming demands of illness; despite the shared goal of improving the patient's condition, partners may ultimately conflict in their individual coping and are unable to re-connect.

Limitations

While all of the "I-We" process codes categorized as "We"-affirming and "We"-differentiating were identified in the current CRC and colostomy sample, either indirectly within the couples' dialogue of their cancer experience, or directly as self-identified shifts

by the couple, not all of the “We”-eroding processes were identified. Specifically, *Inability to Communicate*, *Having to be Strong*, *Ultimately Alone*, and *Emotional Engulfment* were not identified within the current investigation. Given the partners’ high ratings of relationship satisfaction on the Kansas Marital Satisfaction Survey and the Revised Dyadic Adjustment Scale, it is presumed that the current sample of couples were high functioning, which may have aided in their adjustment. In other words, it is possible that these couples had a strong sense of “We”-ness prior to their cancer experience which enabled them to resist engaging in “We”-eroding processes. Future investigations into the current “I-We” classification system may benefit from interviewing couples with lower levels of relationship satisfaction in order to better explore and understand “We”-eroding processes.

The sample in the current investigation consisted primarily of male patients and their female partners because recruitment of female patients and their male partners proved difficult and generally unsuccessful. Investigations into gender differences in adjustment to colorectal cancer suggest that female patients with male partners tend to report lower relationship satisfaction, more distress, and poorer adjustment than male patients (Baider, Perez, & Kaplan De-Nour, 1989; Goldzweig et al., 2009). Given these findings, it is possible that these couples declined to participate due to a tenuous adjustment to the illness and/or colostomy. It also is plausible that such couples may have described experiences consistent with “We”-eroding processes, and would have contributed to further validating those types of “I-We” process codes. Additionally, the inclusion of more female patients and their partners may have provided further gender-specific information pertaining to couple adjustment to CRC and permanent colostomies.

Additionally, the current investigation chose to interview the partners together. The reasoning being that when together, partners may be able to encourage the expression of the other as well as collaboratively recall their cancer experience, and offer their shared as well as individual perspectives on the same events or periods of adjustment. However, it is possible that some patients or partners felt they had to censor themselves or not fully disclose their genuine thoughts and feelings in an effort to protect the other.

It is also important to consider theoretical limitations imposed by the nature of the phenomena of interest and the method by which it was currently studied. Literature in self-identification describes both an “I”, the knower, and the “Me”, the known (Reid & Ahmad, in press). This concept can be extended to the couple, where the “We” is the partners’ mutual identification to the relationship and the dyadic counter to the “Me” (Reid & Ahmad, in press). Each partner’s individual sense of self is crucial to their ability to understand one another and their interactions within the relationship. While the classification is phrased in terms of “I” and “We” because it aims to categorize and describe the particular relationship dynamics and processes in couples’ adjustment to cancer, the mode of inquiry elicits couples’ *representations* of themselves and their experiences, as individuals and as a couple. Thus when partners use the word “I” in the current investigation, they are in fact speaking to their “Me” or what they know about themselves, as well as their shared construction of “Us.” Future research may aim to better access partners’ “I” or *process* of knowing themselves and their relationship

Implications

This classification system as well as its confirmation and further elucidation in the current sample may lead to advancements in clinical work with oncological populations. Specifically, a greater understanding of the fluctuations in couples' cohesive identities that occur in response to cancer has the potential to inform psychoeducational interventions for couples by defining realistic expectations for the types of changes that occur while adjusting to major illness. In conceptualizing adjustment to cancer as an ebb and flow between couples' sense of "I" and "We", clinicians can normalize patients' and partners' needs for separateness or experiences of disconnection and instill hope that these fluctuations are not only common but also hold the potential to affirm their mutual identity.

Moreover, in studying colorectal cancer patients with permanent colostomies as well as their partners, the current investigation helped to further current understanding of dyadic coping within this cancer population. These findings have the potential to inform clinical care providers of the specific concerns and challenges faced by couples adjusting to CRC and colostomies. In turn, clinicians should be better equipped to anticipate and address these issues. As couples commonly discussed challenges to their sexual/intimate relationships as a result of the CRC and colostomy (i.e. *Accepting Changes and Losses Together*), future research may endeavour to address sexual adjustment in CRC patients with colostomies.

On a broader theoretical level, the investigation serves to further our current understanding of couple resilience which has tended to focus almost exclusively on the importance of "We"-ness and the couple's ability to approach the disease in a unified

way (Fergus, 2011; Kayser, Watson, & Andrade, 2007; Skerrett, 1998, in press). When couples are encouraged to tell their relationship stories which are embedded in their “relational epistemology” (Reid & Ahmad, in press) their sense of “We” is made more explicit (Fergus & Reid, 2001; Reid & Ahmad, in press; Skerrett, 2003, 2010). The dialogue brought forth as a result of the interviews helped to highlight that couples’ sense of “We” was demonstrated not only in their discussions of ‘coming together’ but also in their recollection of periods of time when they were honouring of their more separate ways of being in the relationship. The “I-We” classification of couple adjustment to cancer expands our conceptualization of the “We” and its development by illustrating that boundary insertions or shifts toward a sense of “I”, may on the surface at times appear to threaten the “We”, but can in fact reinforce a couple’s connection and ultimate resilience in the face of the illness. Partners’ attunement and respect for one another’s individual needs and separateness speaks to their shared understanding and connectedness. When couples discussed moments in which they provided one another autonomy or space, they conveyed an awareness of the other’s needs and differences. A recognition that partners may desire independence and autonomy during their adjustment does not undermine the “We” but instead serves to honour both “I”s and enhance their individual functioning. As Reid and Ahmad (in press) note, when partners extend their individual self-identification to the relationship, they are more apt to acknowledge and accommodate one another’s differences. As a result, the partners are affirmed of their identification to the relationship, enhancing their shared sense of mutual identity – “We”-ness – and their resilience. This line of thinking in reference to couples’ adjustment to cancer is consistent with the concepts of partners’ possessing ‘differentiated’ versus ‘fused’ “I”s (Karpel,

1976). When partners are ‘differentiated’, they are able to balance both mutuality and autonomy within the relationship. They create trust by being reciprocally sensitive and giving toward the needs of the other. This contributes to the development of a ‘differentiated’ “We”, one that is predicable and stable but also open to change and adjustment in response to challenge.

It is also important to note that findings from the current investigation suggest that even couples who report successful adjustment to cancer and high relationship satisfaction, often experience times of “We”-differentiation and “We”-erosion during their cancer experience. In other words, it appears that it is natural or even inevitable that partners will go through periods of isolation and/or distance over the course of their adjustment to cancer, and that such occurrences do not spell doom for the couples’ ultimate ability to prevail.

Conclusion

This study’s primary aim was to validate an existing classification system of couples’ adjustment to cancer. Using a novel approach to member checking, the classification was assessed for its validity in a different cancer population from those upon which the original classification scheme was developed. With some exceptions, the majority of the original “I-We” process codes were observed in the adjustment experiences of the couples affected by CRC. The current results therefore support the validity of the “I-We” classification system while also providing preliminary evidence of the classification’s analytic generalizability. Future investigations into the application of the “I-We” framework of couple adjustment to cancer may benefit from studying couples

with more diverse sexual orientations, lengths of relationships, and cultural backgrounds as well as those who are less-well adjusted and/or facing different health related crises.

Adjusting to major illness impacts not only the patient but also their partner; by better understanding the common patterns that underlie dyadic coping processes across various type of cancer as well as the unique obstacles presented by different diagnoses, both couples and health care providers will be better equipped to anticipate and overcome the burdens imposed by the illness.

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Appendix A

“I-We” Classification of Couple Coping and Adjustment Processes

Theme	“I-We” Process Code	“We”-ness Impact
Emotional Synchrony	Emotional engulfment	“We”-eroding
	Emotional osmosis	“We”-differentiating
	A journey ending in ‘We’	“We”-affirming
	Accepting changes/losses together	“We”-affirming
	Riding the emotional roller coaster	“We”-affirming
Developing a Dialect	Inability to communicate	“We”-eroding
	Knowing without saying	“We”-affirming
	Finding a shared language	“We”-affirming
	Comfort through touch/proximity	“We”-affirming
Sharing the Burden	Dealing with it on my own	“We”-eroding
	Withdrawing into oneself	“We”-differentiating
	My body, my personal space	“We”-differentiating
	Can’t do it on my own	“We”-affirming
	Granting space/autonomy	“We”-affirming
Carrying/Protecting the Other	<i>Having</i> to be strong	“We”-eroding
	Shielding spouse from illness	“We”-differentiating
	Suffering under the surface	“We”-differentiating
	Keeping this to myself ¹	“We”-differentiating
	Centralizing other	“We”-affirming
	Doing the work of two	“We”-affirming
	Emotional backbone	“We”-affirming
	Preserving ‘I’ identity of other	“We”-affirming
Managing the Illness	Clash in coping styles	“We”-eroding
	Misalignment around healthcare decisions	“We”-eroding
	Illness as a wedge between us ²	“We”-differentiating
	My body, our battle	“We”-affirming
	Safeguarding our little secret	“We”-affirming
	Doing everything we can	“We”-affirming
	Collaborative Caretaking ³	“We”-affirming
Existential Concerns	Ultimate aloneness	“We”-eroding
	Our life without me	“We”-differentiating
	Insidiousness of cancer	“We”-differentiating
	Assuaging other’s aloneness	“We”-affirming

Note. ¹ Originally labeled *Feeling/Thinking the Unspeakable*; ² Newly identified “I-We” Process Code in current sample of CRC patients and their partners; ³ Originally subsumed in *Doing Everything We Can*.

Appendix B

Frequency of Endorsement of “I-We” Process Codes in CRC Sample

“I-We” Process Code	Frequency (n _c)
“We”-affirming processes	
Doing Everything We Can	9
Collaborative Caretaking	9
My Body, Our Battle	8
Accepting Changes/Losses Together	8
Riding the Emotional Rollercoaster	8
Granting Other Space/Autonomy	7
Preserving the “I” Identity of the Other	7
Finding a Shared Language	6
Comfort Through Touch/Proximity	5
Safeguarding Our Little Secret	5
A Journey Ending in “We”	4
Knowing Without Saying	4
Centralizing the Other	4
Doing the Work of Two	4
Emotional Backbone	4
Assuaging Other’s Aloneness	3
“We”-differentiating processes	
My Body, My Personal Space	7
Suffering Under the Surface	5
Our Life Without Me	4
The Insidiousness of Cancer	4
Withdrawing into Oneself	4
Shielding Spouse from Illness	3
Can’t Do It On My Own	3
Keeping This to Myself*	3
Emotional Osmosis	3
Illness as a Wedge Between Us	2
“We”-Eroding processes	
Clash in Coping Styles	5
Misalignment Around Care Decisions	2
Dealing with it on my Own	1
Inability to Communicate	0
<i>Having</i> to be Strong	0
Ultimate Aloneness	0
Emotional Engulfment	0

* Formerly *Feeling/Thinking the Unspeakable*

Appendix C

“I-We” Process Codes as Manifested in Couples Adjusting to Colorectal Cancer and Colostomies

“I-We” Process Code	New information or unique CRC manifestation	Illustrative Quote
“We”-affirming processes		
Doing Everything We Can	CRC couples may learn about the colostomy and its supplies together. May also entail partner taking a more active role in care when patient is too weak (i.e. advocating for patient)	We got pamphlets, and yeah. I went a little bit on the Internet and looked a little bit, but that’s not nice. You find too many things you don’t even want to know [laughs]. But in the beginning it was not easy because you have so many things, when you wanted to order that stuff. So many things to choose from that you go ‘oh my God’ and in the beginning you even order the wrong things. But now we know. (Couple 8, female partner, <i>Episodic</i>).
Collaborative Caretaking	Partners may take a direct (i.e. changing colostomy pouch) or indirect (i.e. monitoring output) role in patient’s physical care related to the colostomy.	[Male patient] has had his colostomy for what, how many years? Five years, honey? He did his first colostomy change by himself when he went with our son out west this summer (Couple 6, female partner, <i>Episodic/Reflective</i>).
My Body, Our Battle	CRC couples may describe experiencing shared bodily changes as a result of the colostomy	Our diet has changed, much to the disagreement of our children (Couple 2, male patient, <i>Linguistic</i>) We did – early on we had a rash, quite a severe one, we even took pictures of it. (Couple 6, male patient, <i>Linguistic</i>) And then we start doing chemotherapy for 4 months (Couple 7, female patient, <i>Linguistic</i>)

Accepting Changes/Losses Together	<p>Many couples commented that their age may have impacted their ability to accept the changes to their sexual/intimate relationship.</p> <p>CRC couples, specifically, must manage challenges imposed by the CRC treatment in their sexual relationship (i.e. pain, embarrassment). Adapting to these changes can include finding alternative sexual activities.</p>	<p><i>Male patient:</i> Well it's not intercourse like it used to be. It's more, like I said, it's mainly masturbation.</p> <p><i>Female partner:</i> Yeah. Well it's oral sex more than anything. (Couple 6, <i>Reflective</i>)</p> <p>I'd be like, oh you know, "Oh here we go, we've got to do it now" and you know. 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] (Couple 1, female patient, <i>Episodic/Reflective</i>)</p>
Riding the Emotional Rollercoaster	No additional information.	<p>It was upsetting at first because we had a lot of younger people that we knew had died that year with cancer like 35 and 45 years old. So we felt pretty blessed that we could have the colostomy do so well (Couple 6, female partner, <i>Episodic/Lingsistic</i>).</p>
Granting Other Space/Autonomy	In CRC couples, respecting <i>physical</i> boundaries requested by the spouse were also important.	<p>When he changes, he does not want me to be around, so that's fine. I accept that. (Couple 8, female partner, <i>Reflective</i>)</p> <p>When I start bathing by myself, he was on call [...] he let the door a bit open in the washroom, [...] And he knew that for half an hour or so, don't talk to me. Nobody show himself or herself in the room. I need to be with myself. (Couple 7, female patient, <i>Episodic</i>)</p>

Preserving the “I” Identity of the Other	In CRC couples, partners’ efforts to uphold the dignity of patients and assure/maintain the normalcy of their physical appearance	<p>I was concerned but on the other hand I understand that he needed time to relax and think about things (Couple 5, female partner, <i>Episodic</i>).</p> <p><i>Female patient</i>: But I got on the internet right away and I found this website called Ostomy Secrets. So it’s like Victoria Secrets, ya know [...] they also showed a “vixen belt” that you could wear for when you’re having sex [...] It was the prettiest little lace belt that I ordered right away. You know with visions that we, you know... [laughs]</p> <p><i>Male partner</i>: So here’s the deal, here’s the deal. So the first time here’s the thing, it’s like “Ya, ya that’s cool” whatever and all that. So then about like the [third] time and whatever. And then it’s like...</p> <p><i>Patient</i>: Don’t even wear it! (Couple 1, <i>Episodic</i>)</p>
Finding a Shared Language	CRC couples are especially concerned with communicating around colostomy and its related activities (i.e. irrigation). Many couples reported naming the stoma, a remarkable way of integrating the colostomy into the relationship and being able to covertly speak about it in public without embarrassment.	<p>We’ve named him, Bob. (Couple 2, female partner, <i>Linguistic/Episodic</i>)</p> <p>Her name is Bertha [...] crazy Bertha (Couple 7, female patient, <i>Reflective</i>).</p> <p>Well when we talk I say, “are you doing your thing?” That’s what we call it [referring to irrigation] (Couple 1, male partner, <i>Episodic</i>).</p> <p>It would be the worst [...] and I’d like say something silly like “Rectum/Wrecked ‘em, darn</p>

		<p>near killed ‘em!’ And then we’d laugh [...] if you’re not laughing, you’re crying. (Couple 1, male partner, <i>Episodic</i>).</p>
Comfort Through Touch/Proximity	No additional information.	<p>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. It’s not only your suffering; it’s my suffering (Couple 3, female partner, <i>Reflective/Episodic</i>).</p>
Safeguarding Our Little Secret	This shift may entail CRC partners discussing if, how, and/or when they would like to disclose diagnosis and/or colostomy to others outside of the relationship.	<p>We stopped in [city] to just kind of talk things over, we stayed a couple of days and that was pretty emotional for us [...] and we hadn’t told our kids, we hadn’t told our friends, like we just kept it all to ours [...] a good place for to collect our own thoughts and have our cries and get emotional and then face the music. (Couple 6, female partner, <i>Episodic</i>)</p> <p>If somebody is just visiting or if we’re visiting somebody, he will explain. Like we went for the adoption classes, we had four days there, so the first day he explained to people who were sitting around the table that this is the problem, I may pass gas, and this is the reason. (Couple 3, female partner, <i>Episodic</i>)</p>
A Journey Ending in “We”	No additional information.	<p><i>Female partner:</i> I would say that it strengthened our relationship because it’s – I think these things, these like traumatic events in your life, if you can</p>

call it that, they can either make you or break you, kind of. And I think it made us. Like I think we were always a strong couple but I think this was you know...

Male patient: It galvanized our relationship.
(Couple 2, *Reflective*)

Knowing Without Saying

No additional information.

Female Patient: He knows my eyes. If not, I told him. But he knows when my body language is “don’t touch me, don’t come close.”

Male Partner: Her face changes. It goes from (angel) to the eyes of a cold – like a laser, coming your way. So we have different ways to communicate. It’s not just to talk (Couple 7, *Reflective/Episodic*).

Centralizing the Other

CRC couples were not consistent with the previous tenant of the definition, stating that female partners tended to make this shift naturally while male partners floundered. While only two male partners were interviewed, they appeared to have quite naturally and willingly centralized the needs of their ill-partners.

I’m here; I’m here for her when she have these things. I used to work in [neighbouring city] and I was under contract, so I did go to work and I got paid, right. So I used to go like early in the morning there, come here like at 3PM, pick her up on the way and go downtown to [hospital] and come back at 8PM. And you know, you get exhausted (Couple 7, male partner, *Episodic*).

Doing the Work of Two

No additional information.

Female partner: Managing everything, I guess, like – when he was first diagnosed, I guess, there was appointments, you know, just taking care of everything was not challenging but it was...

Male patient: Well there was a lot [...] there was

		<p>blood work, there was radiation, there was chemo follow-ups, there was all that stuff.</p> <p><i>Female partner:</i> Well also there's also the kids, and like our life so. And I think I wanted him to focus on himself and be healthy so for me, I guess, I decided to take on everything else and that can be hard and challenging. (Couple 2, <i>Episodic/Reflective</i>)</p>
Emotional Backbone	No additional information.	<p>I remember when [partner] was trying to settle me down at the hospital. I was so agitated [...] I was so agitated, with what was going on and she just tried to calm me down. And that was, I remember, that was very important to me (Couple 9, male patient, <i>Episodic</i>)</p> <p>Actually emotionally and depression wise, he was so much in pain and it's not his fault [...] but there are some things like you do anything, it may not make a difference, so sometimes to take the anger out on the person for no reason, like you see there's no reason, but they cannot shout at the walls, so there is somebody whom they have to take this thing out. So you just have to ignore it, you know the reason behind it, it's not their fault either, but you just have to go through it (Couple 3, female partner, <i>Reflective</i>).</p>
Assuaging Other's Aloneness	No additional information.	<p>We stopped in [city] to kind of talk things over [...] my mom had just passed away with cancer, my</p>

		daughter lost a friend with cancer, and I lost another good friend all young, like my mom was older but all young, and you just kind think, “oh that’s – we’re going to be the next ones.” So those two days I think helped us (Couple 6, female partner, <i>Episodic</i>).
“We”-differentiating processes		
My Body, My Personal Space	Manifested in CRC couples as the patient directly or indirectly requesting separateness due to the colostomy (i.e. privacy during irrigation, covering of stoma)	The other day you had a shower and you came out and you didn’t have the bag on so you just, you can see the stoma, and you kind of cover it up and I was just standing there and I was like ‘You don’t have to do that.’ And he’s like ‘oh’ (Couple 2, female partner, <i>Episodic</i>).
Suffering Under the Surface	As seen in the current sample, this shift can also entail the partner seeking support outside of the relationship as to not burden the patient with his/her worries. Former definition suggested that this shift occurred due to the partner being overwhelmed in their role as caretaker. Noted that in this sample, this shift most often occurred due to a concerted effort on behalf of the partner to prioritize the needs of the patient.	And I know that he goes and cries with my daughter, and my son, and all the friends and all the stuff, but then he comes with me and he tries to be the hero [...] I really appreciate that (Couple 7, female patient, <i>Reflective</i>).
Our Life Without Me	No additional information.	[Partner] was downstairs in the rec room watching you were watching Sleepless in Seattle and remember Tom Hanks was laying there and he had a vision of his wife coming to him and I happened to go downstairs and [partner] was crying and I said, “whatever is the matter?” He said, “well I just

		I just think that's going to be you. You know I thought you're going to be the one alone,"and a that was before we had come to the [hospital] and got everything, but that was an emotional moment for us because you don't think about leaving each other (Couple 6, female partner, <i>Episodic</i>).
The Insidiousness of Cancer	Couples may have a new outlook on life (i.e. pessimism, fear of recurrence) or may gain a new appreciation for one another (i.e. valuing their time together, recognizing new strengths)	I think when this first started, you kind of go "I just want it to be over" and you kind of – everything has a beginning and an end, this doesn't really have an end, right? Once you've had cancer, I don't know, maybe other people are different but once you've had cancer or been with someone who has had cancer, it doesn't just end. It just, it's always there. Even though it's not there everyday now, I mean, it's no [...] the treatments are over but it's still, it doesn't – everything, it's changed. The life we had before, 20 – before cancer, is not the same life we had (Couple 2, female partner, <i>Reflective</i>).
Withdrawing into Oneself	Within the current sample, this shift was also expressed by <i>physically</i> "stepping away" from the cancer experience (i.e. through a solo vacation)	I think he was in a space where he had this time and just – I think you just wanted to be alone. He hadn't really had that time at all since he'd been diagnosed and had treatment. I mean, you were off for your surgery, but then you went back to work and you kinda, you just never had a time. Just to go and think (Couple 2, female partner, <i>Episodic/Reflective</i>).
Shielding Spouse from Illness	No additional information.	He's been very supporting all the time, but during his treatment, he was suffering so I cannot expect

him, but in a way that he did not make things harder for me. If he was lying by himself and I have to be in the kitchen, there were some days I had to cook, he will not just call me and make me sit, he will understand that that thing has to be done too, because it's only me. Even sometimes I used to come in the room and he was crying, but he would not call for me, he would not because I had to spend some time on other things too. But he has been supportive (Couple 3, female partner, *Reflective/Episodic*).

Can't Do It On My Own

Chose to remove clause in former definition stating that this shift may reflect a dependent feeling from the start. These shifts are better captured under *Collaborative Care*. This category represents shifts in the patient from counter-dependence to dependence on the partner.

Whoof, my loss of independence. The ability to drive and do whatever I want when I want [...] [partner] being in control of the money, of the house. Having to depend on someone else doing the decision-making in the house from food to dog to who is coming and going and all that (Couple 7, female patient, *Reflective*).

Keeping This to Myself

Formerly *Feeling/Thinking the Unspeakable*. In the CRC sample, these thoughts included feeling depleted from the treatments and disgust toward the stoma. In this sample, some partners did not explicitly state that they withheld the information but it was assumed that there was a time in the cancer experience that it was not expressed. The shift's name was changed as a result of this observation.

I think the operation, before the operation I'm really worried. You know it was like, oh my God, he's going to have that thing and I didn't I at first didn't even know what it is, [...] and oh 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 and that [...] (Couple 5, female partner, *Episodic*).

Emotional Osmosis	No additional information.	If he cry, I will cry (Couple 7, female patient, <i>Reflective</i>).
Illness as a Wedge Between Us	Newly added shift as a result of the current investigation. Speaks to the physical barrier imposed by the colostomy.	We went on a vacation when the kids were at camp, we went away to Montebello and it was like 40 degrees like this and sitting by the pool wearing a t-shirt like I [did] when I'm outside now and you're swimming and I'm watching you swim. I wasn't allowed (Couple 2, male patient, <i>Episodic</i>)
"We"-Eroding processes		
Clash in Coping Styles	No additional information.	But [partner] tends to ruminate more than I do and [...] we might be sitting reading and all of a sudden she'll say "well what about this", and I wasn't thinking about it at that time. I would say, "I don't wanna talk about that now, we'll wait until find out," you know (Couple 9, male patient, <i>Episodic</i>).
Misalignment Around Care Decisions	Also includes when patient decides to independently pursue treatment options, making the partner feel shut out from decision-making around care.	I don't agree with him looking for like natural thing... I feel like no, he's wasting his time and this cancer is not going to wait it's gonna just, you know, spread because it's already on the – we were told it's stage two (Couple 5, female partner, <i>Reflective</i>)
Dealing with it on my Own	No additional information.	I think not being part of it and wondering if I hadn't supported him enough. Like that suddenly – like, cause, you know, it was almost a year after – it wasn't a year, it was in the fall so it was many months after his diagnosis that he was doing this

[vacation on his own] and I, you know, I worried that, you know, “Is he falling apart now about this? Is this because he hadn’t fallen apart?” and “What does this mean?” (Couple 2, female partner, *Episodic*)

Inability to Communicate	Not endorsed in current CRC sample.
Having to be Strong	Not endorsed in current CRC sample.
Ultimate Aloneness	Not endorsed in current CRC sample.
Emotional Engulfment	Not endorsed in current CRC sample.

Appendix D:

Original “I-We” Classification of Couple Coping and Adjustment to Cancer

“We”-Affirming Processes

DOING EVERYTHING WE CAN

Description: When couple is in agreement around how to approach the disease and treatments including both conventional and non-conventional approaches to treatment. The thrust is working together to eradicate the cancer and/or support the physical well-being of the other person. This may include researching cancer and treatments together or collectively making decisions regarding treatment approaches.

I-We relevance: Both ‘I’s working in unison to ensure the survival of the ill partner and the ‘We’.

Simply put: We are doing everything we can to keep ill partner alive

GRANTING OTHER SPACE/AUTONOMY

Description: Recognizing that the other person needs to separate from oneself in order to process their thoughts and feelings or digest/metabolize this very stressful experience. The well partner is not imposing his/her own personal needs on the other; this is a caring, supportive act in which the partner does not feel excluded or rejected. Also includes granting other the space to choose approach to treatment that works best for him/her and supporting this choice, which can be defined at times as simply not voicing objections to ill-partner’s treatment choices or alternatively as offering agreement with choice in more passive or non-assertive way.

I-We relevance: Although this type of boundary shift appears, on the surface, as one partner distancing him/herself from the other, in actuality, it is expressive of the couple’s togetherness. It is the security of the ‘We’ and the couple bond, and the well-partner’s awareness of the other’s needs, that facilitates such expressions of separateness.

Simply put: The ‘We’ underlies the separation between partners.

RIDING THE EMOTIONAL ROLLER COASTER

Description: When the couple perceives and experiences cancer-related successes, disappointments, and unknowns together as a shared experience; they appraise and/or respond to the positives and negatives together as though they were on the same unique wavelength. This also includes couples united efforts to make lifestyle/relationship adjustments in response to those successes and losses of cancer. This is often demonstrated through consistent, first person plural pronoun use.

I-We relevance: The shared experience of the ups and downs of cancer allows an inherent understanding and appreciation of each partner's emotional volatility, and the perception that this turmoil is not abnormal or unwarranted. In these circumstances, the couple is comforted and bolstered by the presence and understanding of one another throughout the highs and lows of the cancer experience.

Put Simply: The couple perceives and experiences both the positive and negative aspects of the cancer journey together, as evidenced in their 'We' language.

EMOTIONAL BACK BONE

Description: When the partner is successful in creating a safe emotional space for the ill-partner to feel emotionally overwhelmed/a loss of control. Well-partner serves to comfort and contain the ill-partner's distress. Comfort is granted through being a strong, empathetic presence for the other; opposite of the 'We'-eroding shift, *Having to be Strong*. The relationship is more stable as a result of being able to stabilize the other.

I-We relevance: The more vulnerable partner is, in effect, being held/contained by the well-partner in his/her moments of despair/distress.

Simply put: One 'I' working to support/contain the other 'I'

ASSUAGING OTHER'S ALONENESS

Description: When partners attempt to comfort the other, either through emotional support, open communication or physical proximity, from fears of dying. Couples are essentially experiencing/exploring existential themes together.

I-We relevance: Attempting to soothe the fact that the 'We' is comprised of two 'I's.

Simply Put: Couples take a 'We' orientation to death.

COMFORT THROUGH TOUCH/PROXIMITY

Description: When words are not sufficient and touch or physical gestures are a part of conveying and experiencing comfort.

I-We relevance: Physical assertion/manifestation of the 'We' and a reassurance of being a 'We.' The message is that the other is not alone through this experience/in a given moment.

Simply Put: Couples find comfort through a physical representation of 'We.'

FINDING A SHARED LANGUAGE

Description: When a couple goes out of their way to learn how to communicate about cancer, its related losses (e.g., mastectomy, fertility, sexual dysfunction), and death; concepts that may have

been foreign to the couple before. Also entails developing their own idiosyncratic ways of communicating in an adaptive fashion in relation to cancer, whether through the use of humour or non-verbal signals to alert their partner of a need for support.

I-We relevance: This has to do with being able to communicate about very difficult topics, particularly those that threaten the existence or strength of the 'We.' The ability to develop their own shared language or way of communicating helps to join the couple.

Simply put: The 'We' is strengthened by a communal language around losses, cancer, and death.

DOING THE WORK OF TWO

Description: Entails the well-partner taking on roles and responsibilities normally assumed by the ill-partner when they are well. These responsibilities have behavioural and practical emphasis. This shift in roles may then allow the ill-partner to focus his/her attention on treatment/recovery efforts. After treatment, couples may negotiate the re-distribution of responsibilities.

I-We relevance: Task or roles of the patient fall on the shoulders of the well-partner. Thus what was previously distributed among two individuals now becomes one individual's responsibility. The couple's joint ('We') responsibilities are directed to one individual ('I') in the relationship. In this sense there is a movement from an equilibrium within the 'We' of the couple, toward a skew in the direction of one partner or 'I'.

Simply put: What is a 'We' task becomes an 'I' task, at least temporarily.

ACCEPTING CHANGES/LOSSES TOGETHER

Description: When the couple perceives and experiences cancer-related changes or losses together as a shared experience. This pertains especially to a loss of physical functionality or ability, but is also relevant in areas where the couple is forced to surrender a significant or otherwise meaningful portion of their lifestyle or identity as a couple as a result of the diagnosis or treatment of the disease. Feelings of helplessness, hopelessness and grief may be present in these instances in both partners. Although loss of functionality in this instance is typically limited to male prostatectomy patients, a general loss of sexual prowess or capability may also be expressed by female patients whose disease or treatment has affected their sexual identity, confidence or libido. In reference to loss of functionality, part of this acceptance often includes negotiating/developing new ways of expressing their intimacy as a couple or the rationalization that their relationship is much more than sex.

I-We relevance: When a loss of function or desire is experienced and accepted by both partners as a shared loss (i.e., 'our' loss). The grief associated with this loss is shared and reconciled without blame, so that what could be an isolating experience is actually an experience that strengthens or reaffirms the 'We.'

Simply put: This is ‘our’ loss/change to accept/overcome together.

SAFEGUARDING OUR LITTLE SECRET

Description: The couple defines a clear boundary or perimeter between themselves and the outside world. This distinction allows the couple to cope with stigmatizing cancer related concerns together, in private (i.e., news of diagnosis, incontinence). Within this space, each individual is safe to disclose his/her limitations and weaknesses without fear of exploitation or threat of exposure. Each individual’s shortcomings or feelings of vulnerability are accepted by the other and validated implicitly.

I-We relevance: Within the relationship, the self can disclose perceived shortcomings to the other without embarrassment, and the other will not judge or otherwise denigrate the self with this knowledge. In this way, perceived inadequacies become shared ‘We’ inadequacies.

Put simply: The other won’t disclose the self’s secrets; the other will hold this knowledge as if it were his/her own secret to keep and thus the burden of privacy and possibly stigma associated with sickness or disability is shared privately within the couple.

CENTRALIZING THE OTHER

Description: Making the ill partner the centre of the couple by prioritizing his/her needs and desires. Stems from a deep care for the ill-partner, and in some cases may necessitate sacrifices on behalf of the well-partner (i.e., overcoming a fear, sacrificing emotional or physical needs). The female partners seem to do this naturally while male partners often seem to flounder before they get to here. Rather than being two equal ‘I’s the ill spouse assumes the position of being the priority in the relationship.

I-We relevance: The ‘I’ of the ill-partner takes priority over the needs of the ‘We’ or the ‘I’ of well-partner; needs of ill spouse supersede needs of we or other.

Put simply: Needs of well-partner and ‘We’ move down the hierarchy of importance, beneath the needs of the ill-partner

PRESERVING/SUPPORTING ‘I’ IDENTITY OF OTHER

Description: Addresses the task of unobtrusively supporting the partner while being cognizant of the wounds the disease has inflicted upon the other’s identity so as not to accentuate or draw attention to his/her emotional or physical difficulties, disabilities, or losses. Includes the efforts the partner makes to keep things normal, to minimize the damage done to the other’s routine, abilities, and sense of self, especially with regards to a sense of self that has been altered in some way by the cancer.

I-We relevance: The well-partner permits and encourages the expression of the other’s ‘I’ as much as possible in order to minimize the damaging effects of cancer on the ill-spouse’s sense of

self identity. In turn, this assertion of normalcy serves to boost the presence and functioning of the 'We.'

Put simply: The well partner supports other's 'I' in order to help minimize damage to other's identity by disease.

KNOWING WITHOUT SAYING

Description: When partners are so attuned that they can respond to one another's needs without discussion, conversation or direct requests. In some cases this serves to preserve the ill-partner's sense of autonomy and dignity as he/she does not have to request support from their partner and draw attention to their vulnerabilities.

I-We relevance: It is the connection to the other (i.e., shared history) that permits implicit 'knowing' and appropriate/responsive caring of the other's non-verbalized needs.

Simply put: Sense of connection and we-ness so strong that the well-partner implicitly knows the needs of the patient (i.e., 'I' needs) without discussion

MY BODY, OUR BATTLE

Description: When partners take a collective approach to the ownership of cancer. Ill-partner may acknowledge that he/she is the individual who is physically ill, but allows the well-partner to share in the experience. Diagnosis and treatments may be viewed as an experience undergone by both partners. This shift is most apparent through the couples' use of 'We' language (i.e., "we had the radiation"). The couple finds strength and mutual support through sharing the experience. This is the opposite of *My Body, My Personal Space*.

I-We relevance: Cancer becomes a shared 'We' experience even though it is physically isolated to one 'I'

Put simply: Partners draw strength from taking a collaborative orientation to the ownership of the cancer experience.

A JOURNEY ENDING IN 'WE'

Description: Following treatment and recovery, when partners reflect on or identify cancer as a catalyst for strengthening the 'We.' The experience may have fostered a new sense of 'We-ness' or an appreciation for each other that was not present prior to diagnosis or may have reinforced/strengthened their sense of 'We'. Partners may have experienced several shifts between 'We' and 'I' throughout their cancer experience but ultimately identify the journey as 'We'-affirming.

I-We relevance: The cancer experience, no matter how turbulent, creates or strengthens a sense of 'We' at the end of treatment.

Put simply: By the end of treatment, couples are a ‘We.’

“We”-Differentiating Processes

WITHDRAWING INTO ONESELF

Description: Individual overwhelmed by the diagnosis and confrontation with death so withdraws into him/herself. This shift has an emotional emphasis as the individual needs time to digest diagnosis news or other cancer-related experience for him/herself before sharing it with his/her partner. These moments can extend through several days or weeks, or may last a few hours or moments, but are defined as times of isolation from partner often related to existential fears.

I-We relevance: Individual is so overwrought that in essence he/she can’t see or consider the other ‘I’, to do so would be just that much more overwhelming and unmanageable. Experiential recognition of existential aloneness occurs on the level of the individual, not the couple.

Simply put: In such moments the ‘I’ is focal and the ‘We’ very muted or peripheral.

ULTIMATE ALONENESS

Description: When the ill-partner experiences a sense of being overcome by the magnitude of the impending health crisis. This is often described as feeling small, overwhelmed, daunted or the general perception of cancer as a large and foreboding opponent. May also involve existential themes where ill-partner feels alone in death; they view death as a personal or ‘I’ experience that inherently does not involve coping as a ‘We’. The overwhelming nature of these feelings may, despite a strong partnership, push the ill-partner towards feeling as though they alone are going into battle against cancer or death; an almost tunnel vision effect in which the partner cannot provide assistance or support.

I-We relevance: ‘I’ of one partner is isolated by perception of facing looming opponent (cancer), almost as if other partner is displaced from the picture entirely and subconsciously. Presence of cancer overwhelms the other ‘I’ and the ‘We’, so that all that remains is the ‘I’ of the patient versus the cancer/death.

Put simply: ‘I’ of patient is into battle with an opponent (cancer), and there is no focus or attention to the other ‘I’ or the ‘We.’

MY BODY, MY PERSONAL SPACE

Description: Asserting separateness from partner at the level of the body and personal care/hygiene. May be motivated by not wanting to burden the other by the illness/treatment or day-to-day care. Also pertains to ownership by patient – it’s ‘my’ responsibility. Patient does not want to share the responsibility of his/her physical well-being with the other. This shift also pertains to assertions of personal space and not having that personal space ‘invaded.’ Important to note that personal space may be physical space but may also pertain to decision-making

surrounding how to manage physical care. In some cases, can result in disgust, dismissal, embarrassment, and frustration of the self.

I-We relevance: Although disease is situated within one partner's body, it invariably profoundly influences the lives of both partners. The ill-partner is trying to draw a line between self and other in order to take control of the physical aspects of the illness experience.

Simply put: Imposing an artificial division within the 'We' in an attempt to have the illness be about 'I' of the patient at the level of the body

SHIELDING SPOUSE FROM ILLNESS

Description: Trying to prevent the illness from negatively impacting or affecting the well-partner and his/her life (even though this is not possible or realistic). This shift has a protective quality to it. Ill-spouse may experience difficulties with self expression related to this behavior, as other may perceive this protective behavior as isolating or withdrawing or "putting up a wall." Originally developed with patients but can also apply to well-partner (for example, partner who had learned of recurrence before his ill spouse did; or when partner is a health care professional who is more aware of potential negative outcomes that the patient is not aware of).

I-We relevance: Although cancer affects the whole relationship system, the ill-partner tries or wishes to 'buffer' the other from the negative experience, by in effect attempting to make a 'We' experience an 'I' experience by *trying to* restrict or limit its influence on the well partner; trying to contain the effects of cancer.

Simply put: What is a 'We' consideration/experience is artificially assumed by the 'I' in an effort to protect partner from of the disease.

SUFFERING UNDER THE SURFACE

Description: Spouse caregiver is so preoccupied by being the solid support for the other person, that he/she does not attend to his/her own distress/angst. Well-partner is trying to 'hold it all together' but is in fact suffering underneath, suffering in silence. Well-partner may want to protect ill-partner by not burdening him/her with his/her own worry/emotions or feels that above all he/she needs to be a strength and support system for the ill-partner.

I-We relevance: The suffering of the 'I' of the well-partner is hidden or unattended to in his/her effort to provide a solid support for his/her partner and uphold the 'We'. The ill-partner may or may not be aware of this suffering on some level.

Put simply: The well-partner's suffering is pushed under the surface by their desire to provide unwavering support even when he/she is feeling unstable in him/herself.

EMOTIONAL OSMOSIS

Description: The emotions of the other, in particular when polarized, are transmitted to the self and vice versa so that partners' moods are generally matched or similar with one another.

I-We relevance: Partners' moods respond to one another so that they share a collective or 'We' mood rather than separate, individual emotional dispositions.

Put simply: When one partner is down, the other is too.

CAN'T DO IT ON MY OWN

Description: Recognizing that the impact of the illness exceeds the coping abilities of the individual self, and therefore allows the well-partner to assist with the emotional and physical demands of the illness. Ill-partner can't shield other from the disease entirely. This may reflect a movement from a counter-dependent to a more dependent type of coping or may be a reflection of feeling this from the start (i.e., more reflective of an implicit dependency).

I-We relevance: Although the individual may wish to assert independence, and assume full responsibility in dealing with the illness in order to shield or protect the partner or assert his/her own independence, he or she realizes that individualizing the experience is exhausting. Because the demands of the illness exceed the individual's capacity to cope, additional coping resources are sourced through the couple's dyadic connection or sense of togetherness.

Simply put: The 'I' can't do it by itself and needs to open up to the 'We'

OUR LIFE WITHOUT ME

Description: When ill-partner considers well-partner moving on with his/her life without the other's presence. Ill-partner may, for example, fear losing one's place in the life of the couple by being replaced by another woman/man and not having influence in their shared life (i.e. partner, kids, family). May also be when the well-partner reflects on moving on/living life without the ill-partner, including expressing fears related to taking over shared responsibilities and living life alone or with new partner.

I-We relevance: It is difficult to conceive of the 'We' without oneself being present, or when imaging another individual assuming 'I's role.

Simply put: Partner(s) reflect on/image living a life without the current 'We'

THE INSIDIOUSNESS OF CANCER

Description: Life threatening and serious illness has the potential to undermine the 'We' by virtue of taking the life of one partner. Reminder that partners are mortal and will inevitably be separated at some point; often reflected in use of 'We' language. The illness can act like a wedge/force between partners, and often existentially related, fear of death separating the 'We.'

Alternatively, it may help to bring the couple together; offering a new appreciation or new perspective on life with their partner.

I-We relevance: Partners feel the acute, ominous presence or reality of illness/death that threatens the 'We', and can react by either clinging together or alternatively by pulling away from each other.

Simply put: The existence of the 'We' is under threat and partners may be drawn together or pulled apart as a result.

FEELING/THINKING THE UNSPEAKABLE

Definition: When partner has thoughts or feelings that are considered inappropriate or unacceptable and therefore do not get expressed within the marital dyad. For example, being angry toward the ill partner for getting cancer. The impact may ultimately be of a distancing nature between partners, especially in situation where the feeling such as anger is being expressed indirectly. However, it may also be protective of the ill-partner or affirming of the 'We' if the thought/feeling is ultimately expressed and met with non-judgment.

I-We relevance: A thought/feeling of an 'I' is not being expressed within the 'We' and could be either damaging or supporting to the 'We'

Simply put: Inappropriate or unacceptable thoughts are silenced by one 'I' within the dyadic discourse.

"We"-Eroding Processes

MISALIGNMENT AROUND CARE DECISIONS

Description: When couple disagrees about treatment plan, it leads to conflict or becomes a point of tension for the couple, which in turn, impacts their sense of cohesiveness. When ill-partner feels unsupported in his/her decisions, this contributes to a sense of isolation and feeling separate and alone in relation to the other.

I-We relevance: If the couple does not agree on what direction to take with respect to treatment then they are not approaching the illness together. Like a fork in the road, partners then travel down separate paths and it becomes hard for partners to get back on the same track. This leads to an emotional divide within the couple (e.g., anger/resentment; hostility; anxiety).

Simply put: Differing opinions in 'I's force discord/disconnection within the 'We'

DEALING WITH IT ON MY OWN

Description: Reactively or defensively asserting autonomy within relationship at the behavioural/emotional level. This shift has the corollary effect of the other feeling excluded/shut out; in essence disregarding the other person in order not to feel vulnerable oneself or cause

distress in other. The other is effectively denied the opportunity to support the patient or play a role in their care. Ill-partner may do this as a way of taking in information, getting a handle on information before allowing external support from spouse. Includes resistance to role of patient, and simultaneously excludes partner from participating in caregiver role. This shift may be motivated by a desire to not be a burden.

I-We relevance: Not functioning as a 'We'. The natural given and take of support is interrupted by this reactive assertion of 'I-ness'; partner is prohibited from joining the other and tackling the cancer as a 'We'.

Simply put: Other feels shut out by self's desire to cope autonomously.

HAVING TO BE STRONG

Description: When ill-partner feels he/she needs to be strong for the other because his/her partner is incapable of providing support. May include anger and resentment on the part of the ill-partner.

I-We relevance: The self feels isolated and often resentful in response to the other's inability to cope with situation and provide support; feels like they can't turn to/rely on other or 'We' as it's too fragile.

Simply put: In not being able to rely on his/her partner, the patient feels alone in his/her experience with cancer.

CLASH IN COPING STYLES

Description: A clash of individual coping styles whereby the assertion of one's coping approach undermines the other partner's preferred way of coping. This causes a disconnection or rift in the couple's sense of togetherness as they approach the illness or its related challenges from different perspectives. As a result, they may experience difficulty in their ability to identify with their partner and the relationship or communicate about cancer related issues.

I-We relevance: Each "I" coping style (e.g., anxious versus laid back) conflicts and creates tension between partners as they feel they cannot connect or relate to their partner's approach to dealing with the situation. Perception that his/her partner is not on the same level of coping, is not seeing his/her side of the story and not understanding why the other is not having same reactions and feelings. This generates frustration and tension as partners try to get onto the same page and try to understand each other's coping style. Couples who are normally quite harmonious experience this as feeling 'out of synch' with one another.

Simply put: General coping style of self or 'I' clashes with general coping style of other 'I', creating difficulty and friction in trying to access sense of 'We.'

INABILITY TO COMMUNICATE

Description: When partners are not able to speak constructively about the illness because their individual reactions are undermining of their connection. The material is too threatening either to the self or the other to express. Very much about the couple's shared lack of coping and communication rather than about either individual partner.

I-We relevance: Partners feel disconnected and polarized from each other, especially on the emotional level.

Simply put: Without the ability to communicate, 'I's become like magnets repelling each other.

EMOTIONAL ENGULFMENT

Description: When either partner begins to lose sight of his/her own emotions or experience because they are primarily and/or overly concerned with his/her partner's emotions and well-being. This may be in response to misalignment around care decisions or in response to worrying about health of ill partner. May be described as a loss of oneself. Eventually, the overwhelmed partner may have to create an emotional boundary between themselves and their partner in order to re-focus their attention on their own needs and emotions.

I-We relevance: Partner focuses on and adopts the needs and wishes of the other's 'I' while ignoring their own needs/emotions

Put simply: One partner experiences a loss of his/her own 'I' at the expense of the other's 'I'

Appendix E

Consent Form

INFORMED CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Full Study Title: 'I-We' boundary fluctuations in couple adaptation to colorectal cancer and living with an ostomy: A qualitative validation study

Principal Investigator: Karen Fergus, PhD, C.Psych, Patient and Family Support, Sunnybrook Odette Cancer Centre, 416-480-5000 x1243

Co-Investigator: Molly McCarthy, MA Candidate, York University; Debbie Miller, RN, MSN

INFORMED CONSENT

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

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

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

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

INTRODUCTION

You are being asked to consider participating in this study because you or your partner have been diagnosed with locally advanced rectal cancer and have been fitted with a permanent ostomy. Adjusting to cancer can be a challenging experience for both the cancer patient and their partner. The goal of this study is to better understand the ways in which couples adapt to cancer diagnosis and treatment. Most research in this area has focused on patients with breast and prostate cancers. We are specifically interested in understanding the unique issues faced by couples adjusting to colorectal cancer and living with a permanent ostomy. Increasing our understanding

of these issues could help other cancer patients and their partners and help health care providers better address these concerns.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to gain a better understanding of the challenges associated with couples' adjustment to cancer, specifically colorectal cancer and permanent ostomies, and to identify factors which allow couples to cope as well as possible with the illness.

WHAT WILL HAPPEN DURING THIS STUDY?

You and your partner will be asked to attend one interview together and to speak about your experiences with colorectal cancer and living with a permanent ostomy. Interviews will be about about 1.5 hours in length and will take place in a private space at either the Sunnybrook Odette Cancer Centre, or the participant's home. The interview will be audio-recorded. Patients and their partners will also be asked to complete paper-and-pencil questionnaires about relationship satisfaction and overall adjustment. It will take approximately 15 minutes to complete the questionnaires.

You and your partner may be re-contacted at an additional point in time in order to obtain clarification on a point discussed during the interview, or to ask your opinion about a particular finding that arose from the analysis of interviews across participants.

WHAT WILL HAPPEN TO THE INFORMATION YOU PROVIDE THROUGH YOUR PARTICIPATION IN THIS STUDY?

The interview will be audio recorded and transcribed. Transcription is taking the words and dialogue on the audio tape and writing or typing it word for word. All names and identifiers will be deleted during the transcription process. You will not be identified by name on any document and your identity will remain confidential.

The findings will be published in academic journals and presented to professional and general audiences. It is possible that word-for-word excerpts from your discussions and comments may be used in presentations and reports. Were this to occur, your identity would be concealed and protected. However, it is possible that you (or people who know you well) might recognize words-in-print or spoken in a presentation as belonging to you.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

It is anticipated that about 30 people (15 couples) will participate in this study at Sunnybrook. The length of this study for participants is a single appointment, including one interview and a small package of questionnaires. The entire study is expected to take about 2 years to complete and the results should be known in 2 years.

WHAT ARE THE RESPONSIBILITIES OF STUDY PARTICIPANTS?

If you decide to participate in this study you will be asked to complete an interview with your partner and a researcher.

During the interview, you will be asked questions about your experience with cancer and about any changes in your relationship with your partner that occurred over the course of your experience with cancer and the ostomy. In addition to addressing specific topics, you will have the opportunity to elaborate on your thoughts, feelings, and/or concerns related to your experience. You may choose to skip (i.e., not answer) questions you find uncomfortable and/or discontinue participation at any time during the interview.

You will also be asked for some demographic information (e.g., age, education) about you and the type(s) of treatment you have received (if applicable).

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

There are no medical risks to you from participating in this study, but due to the sensitive nature of the research topic, taking part in this study may make you feel uncomfortable. In the unlikely event that you become distressed during the interview, or it becomes evident that you would benefit from counselling, you will have the option of being provided with information regarding psychosocial support services available to you either through the treatment center or in your community. You may refuse to answer questions or stop the interview at any time if you experience any discomfort.

You will be told about any new information that might reasonably affect your willingness to continue to participate in this study as soon as the information becomes available to the study staff.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

You may or may not benefit directly from participating in this study and your participation may or may not help other people with colorectal cancer and/or their partners in the future. However, you will be contributing to the knowledge-base surrounding colorectal cancer patients and/or their partners' experiences with adjusting to cancer and a permanent ostomy. Your participation may also help to inform future research and develop more effective psychosocial interventions which may, in turn, help other patients and/or their partners. There are no medical benefits to you from taking part in this study.

CAN PARTICIPATION IN THIS STUDY END EARLY?

The investigators may decide to remove you from this study without your consent for any of the following reasons:

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

If you are removed from this study, the investigator(s) will discuss the reasons with you.

You can also choose to end your participation at any time without having to provide a reason. If you choose to withdraw, your choice will not have any effect on your current or future medical treatment or health care. If you choose to withdraw from the study at any point, you may request to have the information accumulated up to that point, destroyed.

WHAT ARE THE COSTS OF PARTICIPATING IN THIS STUDY?

Participation in this study will not involve any additional costs to you. If you attend your interview in person at Sunnybrook hospital, you will be fully reimbursed for the cost of your parking.

By signing this consent form, you do not give up any of your legal rights.

ARE STUDY PARTICIPANTS PAID TO PARTICIPATE IN THIS STUDY

You will not be paid to participate in this study. If you decide to participate in this study, you will be reimbursed \$ 25.00 for parking at Sunnybrook Health Care Centre.

HOW WILL MY INFORMATION BE KEPT CONFIDENTIAL?

You have the right to have any information about you and your health that is collected, used or disclosed for this study to be handled in a confidential manner.

If you decide to participate in this study, the investigator(s) and study staff will look at your personal health information and collect only the information they need for this study. “Personal health information” is health information about you that could identify you because it includes information such as your;

- name,
- address,
- telephone number,
- date of birth,
- new and existing medical records, or
- the types, dates and results of various tests and procedures.

You have the right to access, review and request changes to your personal health information.

The following people may come to the hospital to look at your personal health information to check that the information collected for the study is correct and to make sure the study followed the required laws and guidelines:

- Representatives of the Sunnybrook Research Institute, Sunnybrook Health Sciences Centre or the Sunnybrook Research Ethics Board, because they oversee the ethical conduct of research studies at Sunnybrook; and

Access to your personal health information will take place under the supervision of the Principal Investigator.

“Study data” is health information about you that is collected for the study, but that does not directly identify you.

Any study data about you that is sent outside of the hospital will have a code and/or your initials and will not contain your name or address, or any information that directly identifies you.

Study data that is sent outside of the hospital will be used for the research purposes explained in this consent form.

The investigator(s), study staff and the other people listed above will keep the information they see or receive about you confidential, to the extent permitted by applicable laws. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

The Principal Investigator will keep any personal health information about you in a secure and confidential location for 10 years and then destroy it according to Sunnybrook policy.

When the results of this study are published, your identity will not be disclosed.

You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of the results of this study, please provide your name, address and telephone number to the researcher.

DO THE INVESTIGATORS HAVE ANY CONFLICTS OF INTEREST?

There are no conflicts of interest to declare related to this study. The co-investigator is receiving financial payment from the Sponsor to cover the cost of conducting this study.

WHAT ARE THE RIGHTS OF PARTICIPANTS IN A RESEARCH STUDY?

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

If you have any questions about this study you may contact the person in charge of this study (Principal Investigator), Dr. Karen Fergus, Patient and Family Support, Sunnybrook Odette Cancer Centre, 416-480-5000 x1243. The Sunnybrook Research Ethics Board has reviewed this study. If you have questions about your rights as a research participant or any ethical issues related to this study that you wish to discuss with someone not directly involved with the study, you may call **Dr. Philip C. Hébert, Chair of the Sunnybrook Research Ethics Board at (416) 480-4276.**

DOCUMENTATION OF INFORMED CONSENT

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

Full Study Title: 'I-We' boundary fluctuations in couple adaptation to colorectal cancer and living with an ostomy: A qualitative validation study

Name of Participant: _____

Participant/Substitute decision-maker

By signing this form, I confirm that:

- This research study has been fully explained to me and all of my questions answered to my satisfaction
- I understand the requirements of participating in this research study
- I have been informed of the risks and benefits, if any, of participating in this research study
- I have been informed of any alternatives to participating in this research study
- I have been informed of the rights of research participants
- I have read each page of this form
- I authorize access to my personal health information, medical record and research study data as explained in this form
- I have agreed, or agree to allow the person I am responsible for, to participate in this research study

Name of participant/Substitute
decision-maker (print)

Signature

Date

ASSISTANCE DECLARATION

Was the participant assisted during the consent process? ☐ Yes ☐ No

☐ The consent form was read to the participant/substitute decision-maker, and the person signing below attests that the study was accurately explained to, and apparently understood by, the participant/substitute decision-maker.

☐ The person signing below acted as a translator for the participant/substitute decision-maker during the consent process. He/she attests that they have accurately translated the information for the participant/substitute decision-maker, and believe that that participant/substitute decision-maker has understood the information translated.

Name of Person Assisting (Print)

Signature

Date

Person obtaining consent

By signing this form, I confirm that:

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

Name of Person obtaining
consent (print)

Signature

Date

Appendix F

Interview Protocol

A. Cancer History

1. Can you tell me a bit about when you were first diagnosed and what this was like?
(Probe re: feelings/reactions of both partners)
2. What kind of treatments did you receive? (Probe re: coping with treatment; decision-making process in relation to treatment)
3. a. [Directed to Partner]: How do you believe [patient's name] has been coping on an emotional level? (Probe re: worries/concerns; sharing/not sharing of worries or other concerns with partner)
b. [Directed to Patient]: How would you describe your coping? Do you agree or disagree with [partner's name]? Do you have anything you would like to add or revise about your partner's description of your adjustment?
4. a. [Directed to Patient]: How do you believe [partner's name] has been coping on a emotional level? (Probe re: worries/concerns; sharing/not sharing of worries or other concerns with partner)
b. [Directed to Partner]: How would you describe your coping? Do you agree or disagree with [patient's name]? Do you have anything you would like to add or revise about your partner's description of your adjustment?
5. How have you tried to support one another throughout this experience?
6. Can each of you please describe one of the greatest challenges you faced during your experience with cancer? How did you overcome this challenge?

B. Ostomy Challenges

1. Can you tell me a bit about when you learned you would be getting a permanent ostomy?
 - How did you both react to this news? (Probe re: extent to which partner involved in learning about ostomy)
 - What were some of you/your partner's original concerns about the ostomy? Are those still a concern to you now?
2. How do you manage the care of your ostomy? (Probe re: extent to which partner involved in managing ostomy – e.g. buy supplies)
3. Has the ostomy resulted in any emotional discomfort? (i.e. embarrassment, shame). If so, what areas of your life has this affected? (i.e. work, home, sex) Have you avoid any activities because you are concerned about your ostomy?

The next set of questions pertain to your sexual relationship – are you ok with my asking you about this area of your life? (If yes – proceed; if not, skip to Q5)

4. Has the ostomy resulted in any issues of intimacy in your relationship?
 - Have you avoided sexual relations because of the ostomy?
 - Have you experienced difficulty while engaging in sexual intercourse? (i.e. erectile dysfunction in men and lack of lubrication in women)
5. Has the ostomy resulted in any [other] changes to your relationship with your partner?

C. Introducing the ‘I-We’ Model

1. Are there any specific moments during your cancer experience that stand out for you or stick out in your memory, outside of the diagnosis/when doctor told you about the cancer? This moment or event may have occurred during treatment, during the management or adjustment to the ostomy, or during your day-to-day experiences). [look to both the patient and partner while asking this question, probe as to whether these significant moments are different for either of them]
2. [Affirm couples’ overall closeness/positive coping and extent of their experience] Were there any moments when you felt some degree of distance or disconnection, or times when you experienced any level of disagreement? [Probe for specific memory; time, context, individual reactions, resolution]
3. Were there any moments when you still felt close to one another but were more separate in how you coped? [wait for response – if doesn’t yield much then...] Or were there any moments when you still felt close to one another but also felt that it was important to give your partner space or time, on their own?

In some of our previous research with couples adjusting to breast and prostate cancer, we found that couples can go through shifts in their sense of togetherness and ‘separateness’ as they cope with the challenges of the illness. For example, after receiving the news of a prostate cancer diagnosis, one man felt the need to withdraw from his partner so he could digest the news - but in general, this couple was very communicative and close - so this was a change for them. His wife granted him that space at first but eventually intervened so that they could cope together in a more united way. In another case, a woman who underwent a mastectomy for breast cancer asked her husband to give her some physical space – not to touch or come near her scar – until she could heal on her own. Finally, another example is when a man returning home after surgery for his prostate cancer had to manage a catheter and made it clear to his partner that he preferred to be alone in his bathroom activities surrounding the catheter. This was a shift for the couple because they had previously been very comfortable together in the washroom.

So, in a sense, each individual was making a separation or demarcation from his or partner – and this was a change from their normal way of being or interacting with one another. On the surface it might seem that a sense of ‘separateness’ may not be beneficial to a couple, however, some couples described these shifts as helpful especially when they felt their partner was respecting

their boundaries or giving them some time to themselves. The exact examples that I gave may not fit with your own experience but we are interested in finding out whether or not couples adjusting to colorectal cancer have had similar experiences in shifting between a sense of “I” and “We”.

This doesn't have to be in relation to bowel issues specifically but more broadly any shifts you've noticed from what previously was a 'We' or shared way of being/activity to becoming a more singular or 'I' experience/way of being/activity and vice versa. For example, this shift could also be experienced in relation to needing to spend some time on one's own shortly after learning of the diagnosis (moving from “We” to “I” temporarily), or feeling the need to share more than you normally do about your thoughts and feelings (“I” way of being to a “We” way of being).

1. Can you think of any situations where these shifts occurred during your experience in adjusting to cancer?

[if yes]

2. Did you feel a sense of [togetherness/separateness] during your cancer experience?(Probe re: feeling supported by your partner? Why or why not?
3. Can you please describe the situation in which you felt a sense of [togetherness/separateness]? (Probe re: awareness of other; feelings of support; other partners experience of same situation) Any others?
4. Please describe a situation in which you felt the opposite [sense of togetherness/separateness]? (Probe re: awareness of other; feelings of support; other partners experience of same situation)
5. Were there times when you think you may have benefited from the opposite [togetherness/separateness]?
6. Does this I-We model resonate with your experience?
7. Do you find it useful to think about your adjustment to cancer in this way – through an 'I-We' lens? How so/why not?
8. Does it capture your shared experience in adjusting to cancer? What is missing in your view? Do you feel there is a better way to understand or describe your experience?
9. Do you think this might be useful for other couples' adjusting to an illness or traumatic life event? How so/why not?

Appendix G

Demographic and Medical Information Questionnaires

Patient Version

Demographic Information

Your age: _____

Partner's age: _____

Your age at time of diagnosis: _____

What is the *highest* level of education that you have completed? (check only one)

Completed part of high school ☐

Graduated from high school ☐

Completed some college or university ☐

Graduated from university:

Undergraduate degree ☐

Masters degree ☐

Doctoral degree ☐

Other professional degree (e.g., medical, law) ☐

Graduated from college ☐

What is your occupational status?

Unemployed ☐ Employed-full time ☐ Employed-part time ☐

Student- full time ☐ Student-part time ☐ Other _____
(please specify)

What is your ethnicity?

White/Caucasian ☐ Asian ☐ Black/African-Canadian ☐

Native Canadian ☐ Hispanic ☐ Other _____
(please specify)

Relationship Information

What was your marital status *at the time of cancer diagnosis*?

Single ☐ Married ☐ Cohabiting ☐

Separated ☐ Divorced ☐ Widow(er) ☐

In a relationship ☐

What is your *current* marital status?

Single	<input type="checkbox"/>	Married	<input type="checkbox"/>	Cohabiting	<input type="checkbox"/>
Separated	<input type="checkbox"/>	Divorced	<input type="checkbox"/>	Widow(er)	<input type="checkbox"/>
In a relationship	<input type="checkbox"/>				

Number of months/years in current relationship: _____

Time (months/years) between when you were first diagnosed
and start of your current relationship: _____

Family/Living Situation

Children:

Living with:

Partner: _____

Partner and Children: _____

Alone: _____

Health Information

Cancer Diagnosis (Type of Cancer): _____

Month / Year of diagnosis? _____

When did you receive your first treatment? _____

When was your last/most recent treatment? _____

Type of cancer treatment received (please check all that apply):

☐ Surgery

Date: _____

Type of Surgery: _____

☐ Pre-operative Radiation?

Yes _____ No _____

If yes: Frequency and length of treatment: _____

☐ Post-operative Radiation?

Yes _____ No _____

If yes: Frequency and length of treatment _____

☐ Pre-operative Chemotherapy?

Yes _____ No _____

If yes: Frequency and length of treatment _____

☐ Post-operative Chemotherapy? Yes _____ No _____

If yes: Frequency and length of treatment _____

☐ Other: _____

Additional Procedures (e.g. ostomy)

☐ Please describe: _____

Demographic and Medical Information Questionnaire

Partner Version

Demographic Information

Your age: _____

Partner's age: _____

What is the *highest* level of education that you have completed? (check only one)Completed part of high school ☐Graduated from high school ☐Completed some college or university ☐

Graduated from university:

Undergraduate degree ☐Masters degree ☐Doctoral degree ☐Other professional degree (e.g., medical, law) ☐Graduated from college ☐

What is your occupational status?

Unemployed ☐ Employed-full time ☐ Employed-part time ☐Student- full time ☐ Student-part time ☐ Other _____
(please specify)

What is your ethnicity?

White/Caucasian ☐ Asian ☐ Black/African-Canadian ☐Native Canadian ☐ Hispanic ☐ Other _____
(please specify)***Relationship Information***What was your marital status *before you met your partner*?Single ☐ Married ☐ Cohabiting ☐Separated ☐ Divorced ☐ Widow(er) ☐In a relationship ☐

What is your *current* marital status?

Single	<input type="checkbox"/>	Married	<input type="checkbox"/>	Cohabiting	<input type="checkbox"/>
Separated	<input type="checkbox"/>	Divorced	<input type="checkbox"/>	Widow(er)	<input type="checkbox"/>
In a relationship	<input type="checkbox"/>				

Family/Living Situation

Children:

Living with:

Partner: _____

Partner and Children: _____

Alone: _____

Questionnaires – Patient**Kansas Marital Satisfaction Survey****1. How satisfied are you with your marriage/relationship?**

- ☐ Extremely Dissatisfied
- ☐ Very Dissatisfied
- ☐ Somewhat Dissatisfied
- ☐ Mixed
- ☐ Somewhat Satisfied
- ☐ Very Satisfied
- ☐ Extremely Satisfied

2. How satisfied are you with your relationship with your partner?

- ☐ Extremely Dissatisfied
- ☐ Very Dissatisfied
- ☐ Somewhat Dissatisfied
- ☐ Mixed
- ☐ Somewhat Satisfied
- ☐ Very Satisfied
- ☐ Extremely Satisfied

3. How satisfied are you with your spouse as a partner?

- ☐ Extremely Dissatisfied
- ☐ Very Dissatisfied
- ☐ Somewhat Dissatisfied
- ☐ Mixed
- ☐ Somewhat Satisfied
- ☐ Very Satisfied
- ☐ Extremely Satisfied

Revised Dyadic Adjustment Scale

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

	<u>Always Agree</u>	<u>Almost Always Agree</u>	<u>Occa- sionally Agree</u>	<u>Fre- quently Disagree</u>	<u>Almost Always Disagree</u>	<u>Always Disagree</u>
1. Religious matters	5	4	3	2	1	0
2. Demonstrations of affection	5	4	3	2	1	0
3. Making major decisions	5	4	3	2	1	0
4. Sexual relations	5	4	3	2	1	0
5. Conventionality (correct or proper behaviour)	5	4	3	2	1	0
6. Career decisions	5	4	3	2	1	0
	<u>All the time</u>	<u>Most of the time</u>	<u>More often than not</u>	<u>Occa- sionally</u>	<u>Rarely</u>	<u>Never</u>
7. How often do you discuss or have you considered divorce, separation, or terminating your relationship?	5	4	3	2	1	0
8. How often do you and your partner quarrel?	5	4	3	2	1	0
9. Do you ever regret that you married (or live together?)	5	4	3	2	1	0
10. How often do you and your partner “get on each other’s nerves”?	5	4	3	2	1	0
	<u>Every Day</u>	<u>Almost Every Day</u>	<u>Occa- sionally</u>	<u>Rarely</u>	<u>Never</u>	
11. Do you and your partner engage in outside interests together?	4	3	2	1	0	

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

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

Below is a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

PHYSICAL WELL-BEING

		Not at all	A little bit	Some- what	Quite a bit	Very much
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

SOCIAL/FAMILY WELL-BEING

		Not at all	A little bit	Some- what	Quite a bit	Very much
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	<i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box <input type="checkbox"/> and go to the next section.</i>					
GS7	I am satisfied with my sex life	0	1	2	3	4

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

EMOTIONAL WELL-BEING

		Not at all	A little bit	Some- what	Quite a bit	Very much
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness.....	0	1	2	3	4
GE3	I am losing hope in the fight against my illness.....	0	1	2	3	4
GE4	I feel nervous.....	0	1	2	3	4
GE5	I worry about dying.....	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

FUNCTIONAL WELL-BEING

		Not at all	A little bit	Some- what	Quite a bit	Very much
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling.....	0	1	2	3	4
GF3	I am able to enjoy life.....	0	1	2	3	4
GF4	I have accepted my illness.....	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now.....	0	1	2	3	4

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

ADDITIONAL CONCERNS

Not at all A little bit Some-what Quite a bit Very much

C1	I have swelling or cramps in my stomach area	0	1	2	3	4
C2	I am losing weight	0	1	2	3	4
C3	I have control of my bowels	0	1	2	3	4
C4	I can digest my food well	0	1	2	3	4
C5	I have diarrhea (diarrhoea)	0	1	2	3	4
C6	I have a good appetite	0	1	2	3	4
C7	I like the appearance of my body	0	1	2	3	4
Q2	Do you have an ostomy appliance? (Mark one box)	<input type="checkbox"/> No	or	<input type="checkbox"/> Yes		
	If yes, please answer the next two items:					
C8	I am embarrassed by my ostomy appliance	0	1	2	3	4
C9	Caring for my ostomy appliance is difficult	0	1	2	3	4

ILLNESS INTRUSIVENESS RATINGS SCALE

The following items ask about how much your illness and/or its treatment interfere with different aspects of your life. **PLEASE CIRCLE THE ONE NUMBER THAT BEST DESCRIBES YOUR CURRENT LIFE SITUATION.** If an item is not applicable, please circle the number one (1) to indicate that this aspect of your life is not affected very much. Please do not leave any item unanswered. Thank you.

How much does your illness and/or its treatment interfere with your:

1. **HEALTH**

Not Very Much 1 2 3 4 5 6 7 *Very Much*

2. **DIET** (i.e., the things you eat and drink)

Not Very Much 1 2 3 4 5 6 7 *Very Much*

3. **WORK**

Not Very Much 1 2 3 4 5 6 7 *Very Much*

4. **ACTIVE RECREATION** (e.g., sports)

Not Very Much 1 2 3 4 5 6 7 *Very Much*

5. **PASSIVE RECREATION** (e.g., reading, listening to music)

Not Very Much 1 2 3 4 5 6 7 *Very Much*

6. **FINANCIAL SITUATION**

Not Very Much 1 2 3 4 5 6 7 *Very Much*

7. **RELATIONSHIP WITH YOUR SPOUSE** (girlfriend or boyfriend if not married)

Not Very Much 1 2 3 4 5 6 7 *Very Much*

8. **SEX LIFE**

Not Very Much 1 2 3 4 5 6 7 *Very Much*

How much does your illness and/or its treatment interfere with your:

9. FAMILY RELATIONS

Not Very Much 1 2 3 4 5 6 7 *Very Much*

10. OTHER SOCIAL RELATIONS

Not Very Much 1 2 3 4 5 6 7 *Very Much*

11. SELF-EXPRESSION/SELF-IMPROVEMENT

Not Very Much 1 2 3 4 5 6 7 *Very Much*

12. RELIGIOUS EXPRESSION

Not Very Much 1 2 3 4 5 6 7 *Very Much*

13. COMMUNITY AND CIVIC INVOLVEMENT

Not Very Much 1 2 3 4 5 6 7 *Very Much*

Questionnaires – Partner**Kansas Marital Satisfaction Survey****1. How satisfied are you with your marriage/relationship?**

- ☐ Extremely Dissatisfied
- ☐ Very Dissatisfied
- ☐ Somewhat Dissatisfied
- ☐ Mixed
- ☐ Somewhat Satisfied
- ☐ Very Satisfied
- ☐ Extremely Satisfied

2. How satisfied are you with your relationship with your partner?

- ☐ Extremely Dissatisfied
- ☐ Very Dissatisfied
- ☐ Somewhat Dissatisfied
- ☐ Mixed
- ☐ Somewhat Satisfied
- ☐ Very Satisfied
- ☐ Extremely Satisfied

3. How satisfied are you with your spouse as a partner?

- ☐ Extremely Dissatisfied
- ☐ Very Dissatisfied
- ☐ Somewhat Dissatisfied
- ☐ Mixed
- ☐ Somewhat Satisfied
- ☐ Very Satisfied
- ☐ Extremely Satisfied

Revised Dyadic Adjustment Scale

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

	<u>Always Agree</u>	<u>Almost Always Agree</u>	<u>Occa- sionally Agree</u>	<u>Fre- quently Disagree</u>	<u>Almost Always Disagree</u>	<u>Always Disagree</u>
1. Religious matters	5	4	3	2	1	0
2. Demonstrations of affection	5	4	3	2	1	0
3. Making major decisions	5	4	3	2	1	0
4. Sexual relations	5	4	3	2	1	0
5. Conventionality (correct or proper behaviour)	5	4	3	2	1	0
6. Career decisions	5	4	3	2	1	0
	<u>All the time</u>	<u>Most of the time</u>	<u>More often than not</u>	<u>Occa- sionally</u>	<u>Rarely</u>	<u>Never</u>
7. How often do you discuss or have you considered divorce, separation, or terminating your relationship?	5	4	3	2	1	0
8. How often do you and your partner quarrel?	5	4	3	2	1	0
9. Do you ever regret that you married (or live together?)	5	4	3	2	1	0
10. How often do you and your partner “get on each other’s nerves”?	5	4	3	2	1	0
	<u>Every Day</u>	<u>Almost Every Day</u>	<u>Occa- sionally</u>	<u>Rarely</u>	<u>Never</u>	
11. Do you and your partner engage in outside interests together?	4	3	2	1	0	

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

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

ILLNESS INTRUSIVENESS RATINGS SCALE

The following items ask about how much your partner's illness and/or its treatment interfere with different aspects of **YOUR** life. **PLEASE CIRCLE THE ONE NUMBER THAT BEST DESCRIBES YOUR CURRENT LIFE SITUATION.** If an item is not applicable, please circle the number one (1) to indicate that this aspect of your life is not affected very much. Please do not leave any item unanswered. Thank you.

How much does your partner's illness and/or its treatment interfere with YOUR:

1. HEALTH

Not Very Much 1 2 3 4 5 6 7 *Very Much*

2. DIET (i.e., the things you eat and drink)

Not Very Much 1 2 3 4 5 6 7 *Very Much*

3. WORK

Not Very Much 1 2 3 4 5 6 7 *Very Much*

4. ACTIVE RECREATION (e.g., sports)

Not Very Much 1 2 3 4 5 6 7 *Very Much*

5. PASSIVE RECREATION (e.g., reading, listening to music)

Not Very Much 1 2 3 4 5 6 7 *Very Much*

6. FINANCIAL SITUATION

Not Very Much 1 2 3 4 5 6 7 *Very Much*

7. RELATIONSHIP WITH YOUR SPOUSE (girlfriend or boyfriend if not married)

Not Very Much 1 2 3 4 5 6 7 *Very Much*

8. SEX LIFE

Not Very Much 1 2 3 4 5 6 7 *Very Much*

How much does your partner's illness and/or its treatment interfere with YOUR:

9. FAMILY RELATIONS

Not Very Much 1 2 3 4 5 6 7 *Very Much*

10. OTHER SOCIAL RELATIONS

Not Very Much 1 2 3 4 5 6 7 *Very Much*

11. SELF-EXPRESSION/SELF-IMPROVEMENT

Not Very Much 1 2 3 4 5 6 7 *Very Much*

12. RELIGIOUS EXPRESSION

Not Very Much 1 2 3 4 5 6 7 *Very Much*

13. COMMUNITY AND CIVIC INVOLVEMENT

Not Very Much 1 2 3 4 5 6 7 *Very Much*